



Fond du Lac Band
of Lake Superior Chippewa
Wiidookaage Cancer Plan
2007-2012

Fond du Lac Reservation Human Services Division

Mission Statement

The mission of the Fond du Lac Human Services Division is to elevate the health and social well-being of Indian people living in the service area through the provision of services, research, education and employment opportunities.

The photo depicted on the cover is a gift from Jennifer Strickler, Graphic Designer. The photo is of a sunrise over Lake Superior taken in Duluth. The Traditional Flag represents the Fond du Lac Wiidookaage Cancer Program.

BACKGROUND

Wiidookaage is an Ojibwe word meaning, “they help each other.” *Wiidookaage* describes the Fond du Lac (FDL) Reservation’s Comprehensive Cancer Control and Prevention Plan process. “They help each other,” describes how the plan was born, how it evolved into a written plan and how it will be implemented. By the coming together of Fond du Lac community members, tribal leaders, healthcare and social services staff, a wealth of information was gathered to provide a foundation for the plan. The FDL Cancer Team sifted through this information, categorized and developed goals, objectives, strategies and action plans to address many of the issues surrounding cancer in the community. Just as *Wiidookaage* brought the cancer plan into being so will *Wiidookaage* enable the cancer plan to succeed.

The traditional flag pictured on the cover of Fond du Lac’s *Wiidookaage* Comprehensive Cancer Plan depicts how the plan was developed. The staff is a birch tree sapling. The tip of the staff is covered with soft, tanned deerskin. These gifts from Mother Earth provide the base for the traditional flag. The red, black, yellow and white ribbons that secure the deerskin to the tip of the Birch sapling represent the peoples of the world. The many colored ribbon streamers represent many individuals and groups within the Fond du Lac community who contributed to the plan. Tobacco was offered as each ribbon was tied onto the Staff. Building the traditional staff occurred over several months. The *Wiidookaage* flag presides over the meetings of the FDL Cancer Team and is present at events focused on cancer throughout the Fond du Lac community.

The Fond du Lac (FDL) Reservation is a sovereign American Indian nation located in northeastern Minnesota. The reservation lies approximately 25 miles west of Duluth, Minnesota, near the city of Cloquet. The Fond du Lac Reservation service population numbers over 4,500

individuals enrolled in federally recognized tribes with the majority of the members from the Fond du Lac Band of Lake Superior Chippewa. These individuals primarily reside within or nearby the Reservation boundaries. The Indian Health Service User Population in 2006 was 11,635. The Indian Health Service User Population represents the number of individuals who have utilized the FDL healthcare services at least once within the past three years.

Historically, the LaPointe Treaty of September 24, 1854 was the last principle treaty impacting the establishment of the Fond du Lac Indian Reservation. After decades of deterioration within the tribal culture, economic, health, and social status of the tribe the Reorganization Act in 1934 and the Indian Self-Determination Act of 1976 served to gradually revitalize the reservation community.

The Reservation Business Committee (RBC) governs the Fond du Lac Reservation. Elected by the enrolled members of the Fond du Lac Band, the RBC governs all aspects of tribal life including, but not limited to: economic ventures; educational opportunities; environmental matters; hunting, fishing and gathering rights; law enforcement; and healthcare. Through the initiative and support of the RBC the Fond du Lac Human Services Division (FDL HSD) was started in 1974, when the tribe first contracted with the Indian Health Service for the Community Health Representatives program. From this small beginning the FDL HSD has grown into a tribal health and social services delivery system including medical, dental, pharmacy, public health nursing, behavioral health, chemical dependency programming and a wide variety of social services.

Fond du Lac Reservation's

Wiidookaage

Comprehensive

Cancer Plan

2007 – 2012

TABLE OF CONTENTS

| | |
|---|-----------|
| Executive Summary | 6 |
| Introduction | 9 |
| The Cancer Burden of American Indians in Minnesota | 16 |
| The Wiidookaage Comprehensive Cancer Plan | 19 |
| Guiding Statements | 19 |
| Section I: Data/Cancer Registry | 20 |
| Section II: Prevention | 27 |
| Section III: Early Detection | 38 |
| Section IV: Treatment | 44 |
| Section V: Wiidookaage Care <i>From Diagnosis and Beyond</i> | 54 |
| (Palliative Care and End-of-Life Care) | |
| Section VI: Survivorship | 62 |
| Section VII: Caregivers | 71 |
| Section VIII: Evaluation | 76 |
| References | 82 |
| Acknowledgements | 86 |
| Fond du Lac Cancer Program Partners | 88 |
| Fond du Lac Reservation Human Services Division Mission Statement | 90 |

EXECUTIVE SUMMARY

American Indians have the highest cancer incidence and mortality rate of any group in Minnesota. For American Indians, cancer is often diagnosed in advanced stages and many lives are lost because prevention and early detection measures are not in place. The Fond du Lac Human Services Division's healthcare staff became concerned that too many Fond du Lac community members were stricken with, and dying from, cancer. In 2002, determined to change this outcome, the Fond du Lac Reservation Business Committee applied for a planning grant from the Centers for Disease Control to develop a comprehensive cancer plan for the Band. Funding was received in June 2003 and work began to develop a Comprehensive Cancer Prevention and Control Plan for the Fond du Lac community. During the period when the plan was drafted it was discovered an average of 1.5 new cancer cases were diagnosed in the Fond du Lac Community each month.

The Fond du Lac Wiidookaage Comprehensive Cancer Plan defines cancer control activities for the Fond du Lac Reservation from 2007-2012. It was created through a collaboration of Fond du Lac stakeholders including the Reservation Business Committee (tribal council), Fond du Lac Human Services Division administration, public health nursing, medical, pharmacy, dental staff and representatives from the Fond du Lac community including cancer survivors and caregivers as well as several other local, regional, national and Indian Country cancer partners. The plan addresses eight components of comprehensive cancer control:

- ***Data collection:*** To identify gaps, remedy racial/ethnic misclassification, establish a Fond du Lac Cancer Registry, and improve the clinical electronic medical record

system to extract cancer data to drive program planning, implementation and evaluation.

- ***Prevention:*** To increase community awareness of the need to reduce tobacco use and exposure to second hand smoke, follow a healthy lifestyle, have regular cancer screenings; and to increase provider awareness of the most current information in cancer treatments.
- ***Early detection:*** To increase screening rates among Fond du Lac residents through culturally appropriate outreach efforts and elimination of barriers.
- ***Treatment:*** To provide culturally appropriate, holistic, coordinated access to treatment; and provide supportive services to Fond du Lac community members with cancer.
- ***Palliative and End-of-Life Care:*** To include effective pain management.
- ***Survivorship:*** To draw on the strength and wisdom of cancer survivors to help others, and continue to provide services to survivors throughout their lives.
- ***Caregivers:*** To provide readily available information, support and respite to caregivers of people with cancer.
- ***Evaluation:*** To regularly evaluate the effectiveness of the Wiidookaage Comprehensive Cancer Plan in order to make modifications needed to advance the plan.

Each cancer control component is covered in a separate section of the plan. Each section begins with an introduction defining the issue, followed by an implementation plan focused on

one goal with multiple objectives. Each objective has concrete strategies and a specific outcome.

Where appropriate, objectives are assigned a completion date prior to 2012.

INTRODUCTION

Comprehensive Cancer Control is a national program promoting an integrated, coordinated approach to reducing the impact of cancer on the lives of people and communities. It includes monitoring, policy, research, education, programs, services and evaluation.

The Centers for Disease Control and Prevention (CDC) grants funds to states, territories, and Native American tribes to develop and implement plans to address their identified cancer issues. Each plan is unique yet many of the goals are the same. Almost all plans aim to: reduce the incidence of cancer disease within the population; prevent cancer from developing; detect cancer in its earliest stages when it is most treatable; and assure access to quality cancer treatment and supportive services when cancer is diagnosed. Additional goals are: to seek to establish a sound cancer data bases; assist people with cancer to achieve the highest possible quality of life; encourage and utilize the expertise of cancer survivors to give hope to people who are newly diagnosed with cancer; educate communities about cancer disease and the resources and services available to address cancer issues; and to support research to find the ultimate cures for all types of cancer. Healthcare service provision for American Indians in the United States is a complex process governed by Treaties and Federal Law. To effectively address cancer in a comprehensive manner there must be conscious efforts to develop strong partnerships between the tribal government and community; the tribal healthcare delivery system; local, regional and state healthcare systems; Indian Health Service, Indian Country, Federal healthcare programs and with other organizations addressing cancer issues throughout the United States.

***History of the Fond du Lac Band's
Comprehensive Cancer Control Plan***

Over the past three decades the Fond du Lac Reservation (FDL) has expanded its health care and social services capacity to address acute healthcare needs as well as chronic diseases such as diabetes, cardio-vascular disease, arthritis and asthma. During this same period, several Fond du Lac community members were diagnosed with cancer. Supportive health and social services for these individuals and their families were fragmented, often with no interventions provided by the Fond du Lac Human Services Division (FDL HSD) until the cancer disease had advanced to a terminal stage. Cancer research and treatment have progressed substantially during the last three decades and it has become increasingly apparent that cancer disease is treatable, especially when it is detected early. Cancer is even preventable through lifestyle choices and, in the case of colorectal and cervical cancer, through screenings. Improved data collection techniques have also made it clear that the American Indian population in northern Minnesota experienced higher rates of cancer disease and death than other racial/ethnic groups in the United States. The Fond du Lac Reservation Business Committee was determined to rectify this situation.

First Year (2003/2004)

In June 2002 the Fond du Lac Reservation submitted a grant application to the Centers for Disease Control for a Comprehensive Cancer Control and Prevention Planning grant. The grant was funded in June 2003. During the grant's first year, June 30, 2003 – June 29, 2004, the following actions were accomplished:

- A comprehensive cancer program Grant Manager was selected to guide the development of the plan.
- Community focus groups were conducted and individuals interviewed to gather information on:
 - Cancer's impact on the lives of community members.
 - How to address the multi-faceted needs generated by cancer.
 - The best ways to promote cancer prevention and screening for early detection.
- A network of resources for cancer information and support was developed including individuals and organizations from the Fond du Lac community, local counties, regional, state, federal levels and throughout the nation's Indian Country.
- The Fond du Lac Comprehensive Cancer Control and Prevention Team was formed with representation from several departments within the FDL Human Services Division.
- On-going health promotion and education events raised community awareness about cancer disease, prevention, screening for early detection, treatment, support services and survivorship.

- Surveys for mammogram and colonoscopy screenings were conducted to discover the numbers of people being screened and to identify individuals willing to help promote cancer screenings.
- The Fond du Lac public health nursing and social services departments increased outreach to individuals with cancer and their families to offer a variety of supportive services.
- A conference, Cancer Issues in Minnesota's Indian Country, was held June 18, 2004 to educate people about the cancers affecting American Indian people and the resources available to assist people dealing with cancer disease. Approximately 70 people attended the conference.
- For the first time the Fond du Lac community participated in the American Cancer Society's Carlton County Relay for Life event raising nearly \$3,000 for American Cancer Society. The team's 27 members were organized into five clans. Participation in the Relay helped break down barriers to discussing cancer in the Fond du Lac community.
- The cancer plan program manager participated in several educational opportunities to build a current knowledge base about cancer and to network with other people addressing cancer issues, particularly those people involved with American Indian Cancer programs and research projects.

Second Year (2004/2005)

During the second year of the grant, June 30, 2004 to June 29, 2005, work continued, building upon the foundation of the first year, with the following accomplishments:

- Cancer issues identified during the first year were categorized around eight specific areas: ***Data/Registry, Prevention, Early Detection, Treatment, Palliation, Survivorship, Care giving and Evaluation.***
- A resource library of brochures, flyers, handouts, texts and videos was established and used in a variety of community and professional education events.
- The network of people and organizations supporting and providing resources to address Fond du Lac's cancer program was expanded.
- Goals, objectives, strategies, action plans and evaluation processes for each of the eight areas to be addressed in Fond du Lac's *Wiidookaage* Comprehensive Cancer Plan began to be identified.
- A community-based participatory action research project, Cancer, Employment, and American Indians was conducted by Sharon R. Johnson, M.S., CRC, a Fond du Lac tribal member, and Catherine A. Marshall, Ph.D. through the Northern Arizona University.
- A conference, Minnesota Wisconsin American Indian Cancer Conference, was held June 9-10, 2005 drawing over 150 participants from Minnesota and Wisconsin Tribes, local, regional, state and federal organizations interested in addressing the issues surrounding cancer disease among American Indians.

Third Year (2005/2006)

Since June 29, 2005 work expanded and the focus shifted to writing the plan and applying for Implementation grant funding.

Disparity Issues

Indian Health Service (I.H.S.) is the agency within the Department of Health and Human Services that carries out the federal government's trust responsibility to provide health care services to eligible American Indian and Alaska Native people. Over half of the Indian health system is operated directly by tribal governments through contracts or compacts. (I.H.S. Executive Summary 2004). The Fond du Lac Band is a compacted tribal health care program that

Health Disparities Presidential 2010 Goal

- (1) Eliminate disparities in 6 areas of health experienced by racial & ethnic minority populations.
Includes cancer screening and management.
- (2) Identify and address underlying causes: e.g. poverty, lack of access to quality health services, environmental hazards in homes and neighborhoods, and need for effective prevention programs tailored to specific community needs. (Edwards & Swan, 2001)

Healthy People 2010 Goal 2: Eliminate Health Disparities

Among segments of the population, including differences in health that occur by gender, age race or within ethnicity, education or income, disability geographic location or sexual orientation. (Healthy People 2010, 2006)

utilizes federal funding through the I.H.S. along with tribal and other resources to provide health care services for tribal members.

The American Indian population is a disparate population with:

- An unemployment rate that is 2.5 times higher than the rest of the population, per the 1999 unemployment records.

- A poverty rate that is more than 3 times higher when compared to the non-Hispanic white population in 1999 (25.7 % compared to 8.1%).
- Lower education completion (which influence economic prospects) in all education levels, for American Indians aged 25 years and above per the 2000 census. (I.H.S. Executive Summary 2004).

When a tribal health program is unable to provide direct services for an eligible American Indian person the I.H.S. Contract Health Services appropriation may cover the cost of referring patients to hospitals and specialists. However, most health programs deplete their funds prior to the end of the fiscal year. (I.H.S. Executive Summary 2004).

These factors impact the provision of timely cancer screening. Mammography services for breast cancer screening are not available at Fond du Lac's tribal health care clinics; women needing mammograms must be referred out to other health care agencies. This is also true for the colonoscopy services that are important for high quality colorectal cancer screening. (American Indians in Minnesota have the highest rates of morbidity and mortality due to colorectal cancer of all the ethnic groups in Minnesota.)

THE CANCER BURDEN OF

AMERICAN INDIANS IN MINNESOTA

Cancer is the leading cause of death among Minnesota's American Indian population. The Minnesota Cancer Surveillance System reports American Indian men and women have the highest cancer mortality rate by race/ethnicity and gender in Minnesota for the period of 1999-2003. The following statistics demonstrate the disproportionate disparity of cancer related mortality and morbidity for the American Indian populations:

- The cancer mortality rate for American Indian women is 54 % higher than non-Hispanic white women and the cancer mortality rate for American Indian men is 41 % higher than non-Hispanic white men.
- Cancer deaths for American Indian men are primarily due to lung, colorectal, prostate, kidney and esophageal cancer. Cancer deaths for American Indian women are primarily due to lung, colorectal and stomach cancers.
- American Indian men in Minnesota had the highest overall cancer rate with an incidence rate 23 % higher than non-Hispanic white men. American Indian women had an overall cancer incidence rate 7 % higher than non-Hispanic white women.
- The overall cancer mortality and incidence rate for Minnesota American Indians is also more than two times higher than in the United States as a whole for the geographic areas participating in the SEER program. (Minnesota Cancer Facts and Figures, 2006).

- American Indian men in Minnesota have the highest incidence rate of colorectal cancer. Their risk of being diagnosed with the disease is 80 percent higher than for non-Hispanic white men.
- The death rate for Minnesota's American Indian men from colorectal cancer is twice as high as the United States as a whole.
- American Indian men and women have the highest rates of morbidity and mortality due to lung cancer, with the risk of death being twice that of the non-Hispanic population in Minnesota and more than two and a half times greater than in the United States as a whole.
- American Indian men are 4% more likely to be diagnosed with prostate cancer than non-Hispanic white men, and are 60% more likely to die of the disease (Minnesota Cancer Facts and Figures 2006).
- Cervical Cancer, a preventable disease, continues to strike dozens of Minnesota's American Indian women every year.
- Although breast cancer rates are lower in American Indian women in Minnesota their death rate from breast cancer is higher than the other population groups (American Cancer Society 2006).

The Fond du Lac Reservation is part of the Bemidji Indian Health Service Area. This area has the highest cancer mortality rate of all the Indian Health Service Areas, as reported in the Indian Health Service report for the calendar years of 1994-1998. The Community Health Profile: Minnesota, Wisconsin, & Michigan Tribal Communities 2006, produced by the Great

Lakes EpiCenter, reports for 2000-2004 the all-cancer age-adjusted mortality for Minnesota American Indians is 230.5 per 100,000 compared to the Minnesota All Races rate of 182.8 per 100,000. The Healthy People 2010 Goal for all cancer age-adjusted mortality rate is 159.9 per 100,000. It is important to note the data for this report comes from death certificates and may be impacted by racial misclassification. Racial misclassification is a serious problem in collecting accurate cancer data for American Indian populations and may have artificially reduced the mortality rate. Tribal specific cancer data is difficult to extrapolate from the larger cancer data sources.

WIIDOOKAAGE COMPREHENSIVE

CANCER PLAN

Guiding Statements

The people of the Fond du Lac Community will be cancer free.

The Fond du Lac Cancer Team will implement the Wiidookaage Comprehensive Cancer Plan for the Fond du Lac community by:

- Maintaining cancer databases and a Fond du Lac Cancer Registry,
- Promoting the practice lifestyles that will prevent cancer,
- Promoting access to regular cancer screening tests to facilitate the diagnosis of cancer early, when it is most treatable,
- Providing support to people with a cancer diagnosis and their families immediately upon diagnosis,
- Ensuring access to the best possible cancer treatment options,
- Maximizing the quality of life for the person with cancer,
- Providing comprehensive, compassionate end-of-life cares,
- Mobilizing cancer survivors to share their collective wisdom,
- Providing education about prevention, early detection, treatment, survivorship, palliative support and care,
- Creating support systems for caregivers, and
- Establishing and maintaining the effective evaluation process necessary to track progress and advance the comprehensive cancer program.

SECTION I:

DATA/CANCER REGISTRY

Introduction

Access to data is a critical component for any planning process. Data provide the statistical support in establishing the need for programming and services within a healthcare service delivery system. Data are also necessary to measure progress when a plan is implemented. Accurate data for the American Indian population are difficult to obtain. Misclassification of race/ethnicity or lack of collecting race/ethnic information from the person with cancer has contributed to this data problem. Healthcare services for American Indians are complex and fragmented. Even when data are collected it is difficult to consolidate and analyze.

Quantitative Data

B.K. Edwards and J.C. Swan from the National Cancer Institute (2001) stated that cancer surveillance requires ongoing data collection in order to:

- Provide a quantitative portrait of cancer and its determinants in a defined population.
- Measure cancer incidence, morbidity, survival and mortality.
- Assess genetic predisposition, environmental and behavioral risk factors, screening practices, and quality of care—from prevention through palliation.
- Tell us where we are in the effort to reduce the cancer burden.
- Generate observations that form a basis for cancer research and interventions for cancer research and control.

Burhansstipanov and Satter (2000) cautioned us to remember that there is no pan-American Indian group for which aggregated data applies. Specifically, this means that the issue for public health interventions is that [existing] data are insufficient to describe the health status of a tribe. Sufficient data related to health status are necessary to make informed policy, planning, and resource allocation decisions for the health improvement of the population (p. 1722).

American Indian peoples, representing approximately 1% of the United States population (<http://www.census.gov/prod/2001pubs/mso01aian.pdf>), have been described as “invisible.” Tribe-specific data are needed to solve this problem—to make the invisible visible (Marshall, 2001).

In attempting to address disparities of access to health and human services, researchers, program planners, and policy makers concerned with American Indian issues have grown weary of seeing American Indian quantitative data, even when presented in aggregate and thus providing the largest possible numbers, labeled with some form of “DSU = data statistically unreliable” (Murray, 2003, p. 224). As one solution, practitioners and researchers have recommended oversampling and pooling of data (Murray, 2003; Schacht, White, Daugherty, LaPlante, & Menz, 2003), as well as the inclusion of qualitative data (Marshall, Sanders, & Hill, 2001).

Still, local solutions to disparities of access call for disaggregated and tribally specific data. Such documentation is needed to enable state and tribal programs to develop or improve local services that will lead to an increased quality of life among American Indians. Too often, “no data” have been interpreted to mean “no problem” (Burhansstipanov and Satter, 2000) and large, nationwide surveys often have missing, inaccurate, or misleading data for American Indians. Insufficient and inaccurate health data not only provide an unreliable basis for tracking diseases,

but also fail to provide the means for identifying the health needs and strengths of American Indian and Alaska Native individuals, families, and communities—information needed for prevention of disease and for building on health strengths and resources (Schacht, White, Daugherty, LaPlante, & Menz, 2003).

Qualitative Data

In support of qualitative data collection, Murray (2003) reported, “more research . . . should use qualitative and ethnographic methods to examine risk [and] evaluate the effectiveness of interventions” (p. 224). Hughes, Seidman, and Williams, 1993 have argued for “culturally anchored” data collection methods. In her book Decolonizing Methodologies: Research and Indigenous Peoples (1999), Smith noted, “story telling, oral histories, the perspectives of elders and of women have become an integral part of all indigenous research” (p. 144).

Ensuring that data collection methods are both culturally appropriate and rigorous is essential for (1) better understanding health disparities and disparities in access to health and human services, and (2) the design and evaluation of evidence-based interventions to eliminate such disparities.

The Fond du Lac Wiidookaage Cancer Plan has identified the multi-faceted, problematic cancer data situation impacting cancer issues within its community. This problem is addressed through the Data/Cancer Registry Section with a specific goal and a number of objectives and strategies. These objectives and strategies represent activities that will be implemented to provide a solid cancer database to chart Fond du Lac’s progress in comprehensive cancer programming and services.

Implementation

Goal:

Assess cancer data needs by identifying the gaps in existing data to pinpoint where cancer prevention and control efforts should be targeted. These data will be used to establish achievable objectives and evaluate progress for the Fond du Lac Reservation.

Objective 1:

Establish baseline data for the American Indian service population of the Fond du Lac Reservation by June 29, 2009.

Strategies:

1. Enhance the NextGen Medical Records System to allow for cueing, entering and extrapolating baseline and continuing cancer data.
2. Establish collection of baseline and continuing data for client cancer history.
3. Establish collection of baseline and continuing cancer data collection for:
 - Mammograms
 - Pap Tests
 - PSA
 - Colorectal screening tests
 - FOBT
 - Flexible Sigmoidoscopy
 - Colonoscopy
 - Skin Inspection
 - Number of American Indian persons within FDL service area with cancer diagnosis
 - Number of American Indian persons within FDL service area with cancer diagnosis receiving cancer treatment
 - Types of cancer for persons with cancer diagnosis
 - Source of cancer treatment

- Personal use of tobacco
- Family history of cancer.

Expected Outcome:

Improved use of data to identify Fond du Lac Reservation's cancer prevention and control needs.

Objective 2:

Establish a Cancer Registry for the Fond du Lac Reservation population.

Strategies:

1. Develop computerized Fond du Lac Cancer Registry recording demographic information including family history of cancer; type of cancer; date of diagnosis; stage at diagnosis; treatment and outcome information.
2. Incorporate existing Fond du Lac Cancer Registry data into the computerized Fond du Lac Cancer Registry.
3. Ensure the capacity of the computerized Fond du Lac Cancer Registry to provide detailed reports as needed for cancer statistics within the population while respecting the privacy and confidentiality of individuals listed in the Registry.

Expected Outcome:

Increased surveillance capabilities.

Objective 3:

Eliminate misclassification of race and ethnicity for individuals from Fond du Lac community who appear on or are missing from the Minnesota Cancer Registry by June 29, 2010.

Strategies:

1. Collaborate with North Central Spirit of EAGLES to implement Cancer Surveillance Research Improvement Project for Fond du Lac Reservation.
2. Collaborate with Minnesota Cancer Surveillance System to integrate findings from the Fond du Lac Reservation Cancer Surveillance Research Improvement Project into the Minnesota Cancer Surveillance System.
3. Collaborate with Indian Health Service to seek ways to integrate the FDL cancer data into the Indian Health Service database system.

Expected Outcome:

Standardization of race and ethnicity data across all records.

Objective 4:

Establish a system to gather and monitor tobacco use in Fond du Lac Reservation public areas by June 29, 2008.

Strategy:

1. Develop a data collection system to establish a baseline of smoke-free and smoking-allowed public areas within the Fond du Lac Reservation and monitor annually for changes in Smoking Allowed or Smoke-free status of all Fond du Lac Reservation public areas.

Expected Outcome:

Increased surveillance capabilities for tobacco cessation program.

Objective 5:

Share results of cancer surveillance gathered through data collection with the Fond du Lac community, Reservation Business Committee and Fond du Lac Human Services Division health and social services care providers.

Strategies:

1. Provide annual reports of cancer surveillance data to FDL HSD Main CQI Committee, FDL HSD administration and department coordinators.
2. Publish cancer surveillance findings in the tribal newspaper and tribal web site on an annual basis.
3. Present cancer surveillance findings to the Reservation Business Committee and FDL HSD Advisory Board on an annual basis.

Expected Outcome:

An increased awareness of cancer and expanded cancer control programming.

SECTION II:

PREVENTION

Introduction

Cancer is a group of diseases characterized by the uncontrolled growth and spread of abnormal cells. If the spread is not controlled, it can result in death. Cancer is caused by both external factors (tobacco, chemicals, radiation and infectious organisms) and internal factors (inherited mutations, hormones, immune conditions, and mutations that occur through metabolism). (American Cancer Society, Cancer Facts & Figures 2006).

The American Cancer Society estimates that in 2006 there will be approximately 1,400,000 new cancer cases diagnosed. An estimated 170,000 deaths will be related to tobacco smoke (e.g., male smokers are 23 times more likely to develop cancer than male non-smokers) and could be completely eliminated. Scientific evidence suggests that an additional one-third of cancer deaths will be related to nutrition, physical inactivity and being overweight. Community education on healthy lifestyles is an essential component of cancer prevention. Because 76% of all cancers are diagnosed in persons 55 and older, this education needs to include intensive outreach to community elders. Certain cancers are related to infectious agents including the hepatitis B virus (HBV), human papillomavirus (HPV), human immunodeficiency virus (HIV) and helicobacter and can be prevented through behavioral changes, vaccines or antibiotics.

Cancers that can be prevented or detected earlier by screening account for at least half of all new cancer cases. Regular screening examinations by a health care professional can prevent cervical and colorectal cancers through the discovery and removal of precursor lesions.

Screening can detect cancers of the breast, colon, rectum, cervix, prostate, oral cavity and skin at early stages. The five-year relative survival rate for these cancers is about 86%, and reflects a real reduction in mortality.

Between 5 – 10% of all cancers are strongly hereditary, so that knowledge of cancer patterns within families is necessary for timely screenings.

Because the recommendation of their provider is the major reason people have screenings, adherence to a consistent set of screening guidelines and ongoing provider education regarding the benefits of cancer screenings is vital.

Behavior patterns and lifestyle choices clearly impact cancer risk yet many people do not recognize the power they have to alter their risk of disease. To successfully reduce the burden of cancer in our society, we must increase the awareness of prevention strategies in our patients and our communities (Colitz & Stein, 2004). Prevention is the most powerful factor in decreasing cancer morbidity and mortality today (Robert Hiatt, 2006). During the past two decades the Fond du Lac Reservation has implemented programs through its FDL Human Services Division to address diabetes and cardiovascular disease. One of the major focuses of these programs is prevention of these diseases through healthy lifestyle choices. Incorporating cancer prevention into these established programs is part of the FDL Wiidookaage Cancer Plan.

Tobacco is the single most important challenge for Fond du Lac in decreasing cancer morbidity and mortality. With smoking rates over 50% within the Fond du Lac population,

tobacco cessation and education to deter use of tobacco in non-ceremonial ways is critical to changing the pattern of cancer within the Fond du Lac population.

Tobacco was given to the Native American people as a gift to help us in our prayers to the Creator, and to give thanks for every day we get to experience. Traditionally, tobacco was also meant to be used for seeking protection, seeking advice, when hunting to give tobacco for the life of the animal, to seek spiritual guidance or advice, at the initiation of ceremonies, as a medicine, when going to gather sage or sweet grass as an offering. What is happening now is that by abusing the gift that we were given, we are learning the negative effects it can have on us as a people. (Lung cancer, in our elders, and chronic ear infections, and asthma in our babies, not to mention the secondhand smoke issue).

We as a people are not only in need of our education and cessation program, but Native Americans in general are in need of going back to using the gift of tobacco as it was meant to be used, not by abusing it.

The national smoking rates are nowhere near representative of what reality is for the relatively "Small" population of Native Americans.

The Wiidookawishin Quitplan program (Fond du Lac's smoking cessation program) is planning to revitalize the Asema is Sacred philosophy in hopes to eliminate the abuse rate, and increase the ceremonial use of tobacco.

—Dara Topping, Community Member

Implementation

Goal:

Promote the prevention of cancer disease through healthy lifestyles, physical environments and healthcare interventions that reduce cancer risk for the Fond du Lac Reservation population.

Education: Community

Objective 1:

Increase the knowledge of cancer prevention among the Fond du Lac community members through culturally specific education interventions by December 2007.

Strategies:

1. Establish community education events featuring cancer disease prevention information for:
 - Breast Cancer
 - Colorectal Cancer
 - Lung Cancer
 - Prostate Cancer
 - Cervical Cancer
 - Skin Cancer
 - Other Cancers
 - Healthy Life Styles: Wellness
2. Provide cancer prevention education displays for the community at healthcare clinics, community-gathering places, Powwows, community health related events and tribal programs such as schools and work sites.
3. Identify individuals, cancer survivors and health and social services providers from within the Fond du Lac community willing to serve on a Speakers Bureau and speak publicly on cancer topics for Fond du Lac community events.

4. Disseminate cancer prevention information through paycheck mailers, tribal newspaper articles and other mass communication venues.
5. Provide web links to appropriate cancer information resources through the Public Health Department web page for the Fond du Lac Reservation Web Site.
6. Design and produce a culturally specific brochure promoting the Fond du Lac Wiidookaage Comprehensive Cancer Plan to community.
7. Collaborate with tribal, federal, national, state and local cancer partners to develop or acquire educational and information resources.
8. Use the Guide to Community Preventive Services from Centers for Disease Control to assist in planning interventions.

Expected Outcome:

Increased awareness of cancer prevention behaviors.

Education: Health and Social Service Providers

Objective 2:

Improve professional knowledge, understanding of cancer prevention, and provision of services that prevent cancer through education and training for Fond du Lac Health and Social Services care providers by December 2007.

Strategies:

1. Provide continuing education opportunities for Fond du Lac Health and Social Services care providers focused on cancer prevention topics including but not limited to:
 - Healthy Life Styles: Wellness
 - Obesity and Cancer

- Tobacco Use and Cancer
 - Nutrition and Cancer
- 2. Increase awareness of and access to professional educational materials for cancer prevention by identifying credible cancer information resources and culturally specific resources and disseminating this information to all Fond du Lac Health and Social Services care providers.
- 3. Assess, monitor, promote and provide Hepatitis B vaccination series for people of all ages to prevent one type of liver cancer.
- 4. Monitor and prepare to implement the Human Papilloma Virus vaccination when it becomes available, to decrease incidence of cervical cancer.

Expected Outcome:

Increased Fond du Lac Health and Social Services care providers' focus, knowledge and skills regarding cancer prevention, client education and interventions.

Healthy Lifestyles: Nutrition and Exercise

Objective 3:

Partner with other Fond du Lac healthcare programs addressing healthy lifestyles, wellness behaviors and disease prevention, especially the programs focused on Diabetes and Cardiovascular Disease prevention to promote behaviors to reduce cancer risk by December 2009.

Strategies:

1. Collaborate with the *On the Move* exercise program to include information on the benefits of exercise in preventing cancer.

2. Collaborate with Fond du Lac Human Services Division's Nutrition Programs (dieticians, Diabetes program, Cardiovascular program, Public Health Nursing Community Nutrition program, Women, Infants and Children program, etc.) to include information on the impact of healthy diet and healthy weight on cancer prevention.
3. Create a culturally specific community campaign to educate Fond du Lac community members about cancer fighting foods.
4. Work with other Fond du Lac Reservation Tribal organizations to increase easy access to exercise: increasing safe walking trails; allowing time for exercise within the work hours; establishing employee wellness programs; and encouraging the Fond du Lac Health Insurance Board to adopt programs to promote healthy life styles.

Expected Outcome:

Increased awareness and knowledge among Fond du Lac healthcare providers and community members of the impact of exercise and nutrition in preventing cancer.

Healthy Lifestyles: Tobacco Cessation

Objective 4:

Fond du Lac Reservation will reduce non-ceremonial tobacco use to 40% of population by December 2010.

Baseline: 2003 Fond du Lac Reservation Needs Assessment: 56.1%

2005 Fond du Lac Reservation Needs Assessment: 45.3%

Strategies:

1. Establish a protocol in Medical and Dental Clinics to ask patients/clients age 12 and above about current smoking behavior. If they are smokers, they will be asked if they are interested in quitting. If so, staff will offer education on smoking cessation and referral to the Public Health Nursing Department's smoking cessation program.
2. Work with Pharmacy to increase variety of medications to assist individuals who are in a smoking cessation mode.
3. Increase collaboration between Fond du Lac Human Public Health Nursing Tobacco Cessation Program (funded through a Clearway grant), Clinic, Pharmacy, Dental and Behavioral Health Departments in addressing nonceremonial tobacco use.
4. Increase culturally specific Tobacco Abuse education within tribal school curriculum.
5. Utilize age-specific, culturally appropriate tobacco use education materials in health programs and community education programs within the Fond du Lac community.
6. Develop a Smoking Cessation Support Network encouraging individuals in age-specific networks to call others for support and partner in healthy lifestyle activities instead of smoking cigarettes.

Expected Outcome:

Decrease in tobacco use rate within the Fond du Lac community.

Objective 5:

Reduce secondhand smoke exposure within the Fond du Lac community by December 2010.

Strategies:

1. Work with the Reservation Business Committee to expand smoke-free environments throughout the Reservation: work sites; tribal businesses; community gathering areas; and service providing sites. Advocate for a Tribal Resolution to have all Fond du Lac Reservation public places and events smoke-free.
2. Increase education regarding the dangers of secondhand smoke to unborn babies, children/youth, non-smokers, the elderly and others with chronic health conditions.
3. Increase smoke-free community events.
4. Support smoke-free homes within the Fond du Lac Reservation community through a smoke-free homes campaign rewarding families who designate their homes as smoke-free.

Expected Outcome:

Reduced exposure to second-hand tobacco smoke.

Access to Cancer Information***Objective 6:***

Increase opportunities for individual Fond du Lac community members to access cancer information independently by December 2008.

Strategies:

1. Establish a Community Cancer Resources Center within a section of the Fond du Lac Tribal Center Community Library.
2. Promote access to cancer prevention information links on the Fond du Lac web site through public computers available at the Fond du Lac Tribal Center Community Library.
3. Partner with American Cancer Society, Mayo Clinic Native Programs, Native American Cancer Research, Cancer Information Services, Centers for Disease Control, Lance Armstrong Foundation and other nationally recognized cancer information services to help establish the Community Cancer Resource Center with current cancer information.
4. Make culturally specific cancer related literature and resources are available in the Community Cancer Resources Center.

Expected Outcome:

Enhanced opportunities for Fond du Lac community members to independently access cancer prevention information.

Environmental Carcinogens

Objective 7:

Assess, identify, and develop interventions to reduce potential cancer causing toxins that may exist within the Fond du Lac Reservation properties by December 2012.

Strategy:

1. Collaborate with the Fond du Lac Environmental Protection Department, Public Health and Environmental Services to develop a program to address potential carcinogens within the Fond du Lac community properties.

Expected Outcome:

Decrease in potential exposure to carcinogens for Fond du Lac community members.

Awareness of Family Cancer History***Objective 8:***

Increase awareness of the importance of familial cancer history among Fond du Lac community members and healthcare providers by December 2009.

Strategies:

1. Develop culturally specific education materials for the community focused on family cancer history and cancer prevention.
2. Establish a system to routinely gather familial cancer history during health care appointments.

Expected Outcome:

Enhanced awareness of familial cancer history to provide opportunities to prevent cancer.

SECTION III:

EARLY DETECTION

Introduction

Early detection is key to reducing mortality for many types of cancer. Early detection of cancer includes two core components: education and screening. Education efforts must promote public awareness of the early signs of certain cancers (oral cavity, larynx, colon, rectum, skin, breast, cervix, urinary bladder and prostate). Efforts must also include proper follow-up procedures with healthcare providers if cancer symptoms are present. The burden of cancer in a population, availability of effective treatment and evidence of benefits and cost-effectiveness, all determine whether or not screening should be implemented in a population group. Early detection can help reduce cancer mortality, however it is dependant on proper diagnostic and treatment follow-up, the health service infrastructure and target population compliance. (Mackey, Jemal, Lee and Parkin, 2006) Screening tests for cervical and colorectal cancers may actually prevent these cancers from developing by detecting pre-cancerous conditions (CDC, 2005).

The Fond du Lac Reservation faces many challenges in establishing an effective cancer screening program. Fear of cancer diagnosis, access barriers, financial issues and lack of knowledge about the benefits of cancer screening hinder cancer screening efforts. Cultural aspects such as modesty keep individuals from submitting to cancer screening tests. Mammography services for breast cancer screening are not available at Fond du Lac's tribal health care clinics. Women needing mammograms must be referred out to other health care

agencies. This is also true for colonoscopy services that are important for high quality colorectal cancer screening. American Indians in Minnesota have the highest rates of morbidity and mortality due to colorectal cancer of all the ethnic groups in Minnesota.

Implementation

Goal:

Assess needs of, capacity for, and gaps in cancer screening services at Fond du Lac Reservation while developing programs and protocols to increase access to and utilization of cancer screening services for Fond du Lac community members.

Objective 1:

Increase culturally specific outreach activities within FDL community to improve cancer screening rates by December 2008.

Strategies:

1. Partner with American Cancer Society to implement cancer-screening outreach programs utilizing Community Health Representatives and/or a Community Outreach Worker.
2. Focus on increasing cancer screening for:
 - Breast:
 - Clinical Breast Exam
 - Mammograms
 - Colorectal:
 - FOBT
 - Flexible Sigmoidoscopy
 - Colonoscopy
 - Prostate:
 - PSA
 - Cervical:
 - Pap Test
 - Skin:

- Visual exam
- 3. Develop culturally specific, evidence-based “best practice” outreach programs to increase participation in cancer screening tests.
- 4. Develop cancer outreach programs for male Fond du Lac community members that are culturally specific and focused on men’s cancer issues.
- 5. Promote early screening for cancer through cancer education literature placed in prescription bags distributed by Pharmacy Staff.
- 6. Increase community awareness of cancer burden within American Indian population in Minnesota and Fond du Lac through community education activities.
- 7. Provide web links to appropriate cancer information resources through the Public Health Nursing Department’s web page for the Fond du Lac Reservation Web Site.
- 8. Partner with the Minnesota Cancer Alliance Community Health Worker Project to increase the work force available to address cancer outreach and navigation needs through the Fond du Lac Tribal and Community College.

Expected Outcome:

Increased cancer screening rates among Fond du Lac community members.

Objective 2:

The Fond du Lac Human Services Division healthcare providers will utilize a consistent set of cancer screening standards by December 2009.

Strategies:

1. Establish a consistent set of cancer screening standards that are based on current cancer research. Ensure that all Fond du Lac Human Services Division healthcare providers use these standards.
2. Collaborate with local and regional Cancer Centers to provide professional continuing education opportunities for Fond du Lac Human Services Division healthcare providers related to cancer screening interventions.

Expected Outcome:

Increased number of Fond du Lac Human Services Division healthcare providers assessing need for, and promoting, as appropriate, regular cancer screening with their clients.

Objective 3:

Increase cancer-screening rates for Fond du Lac community members utilizing the Fond du Lac Healthcare Clinics by December 2010.

Strategies:

1. Develop Client Recall System “Tickler File” for Fond du Lac Clinics to use to remind clients of cancer screenings: mammograms, pap tests, colorectal cancer screening and prostate cancer screening.
2. Assure all clients age 12 years and above receive routine screening for oral cancer during dental examinations.

Expected Outcome:

Increase in Fond du Lac community members regularly screened for cancer through the Fond du Lac Healthcare Clinics.

Objective 4:

Fond du Lac Human Services Division healthcare providers will assess all clients for familial cancer history by December 2010.

Strategies:

1. Enhance NextGen Computerized Medical Record to provide cueing for healthcare providers to obtain and review familial cancer history with clients.
2. Initial focus on colorectal, breast and ovarian cancers.
3. Utilize cancer partnerships to identify experts in the field of genetics and cancer to provide education for Fond du Lac Human Services Division healthcare providers.
4. Educate Fond du Lac community members about genetics and cancer risk through a variety of community outreach activities.

Expected Outcome:

Increased awareness of the potential role of genetics and increased cancer risk by members of the Fond du Lac community.

Objective 5:

Eliminate barriers to accessing regular cancer screening by 2010.

Strategies:

1. Increase collaboration between Fond du Lac Human Services Division healthcare providers and social service providers to identify and increase access to financial support for off-site cancer screening costs.
2. Partner with Duluth YWCA to provide access to low cost and free mammograms through the Minnesota Department of Health SAGE program for American Indian women in the Fond du Lac service area.
3. Partner with American Cancer Society to implement a Volunteer Driver program within Fond du Lac community to enhance transportation options to cancer screening facilities.

Expected Outcome:

Increased cancer screening rates among Fond du Lac community members.

SECTION IV:

TREATMENT

Introduction

Cancer treatment typically involves several medical interventions: surgery, chemotherapy, radiation, hormonal treatments and immunotherapy. The treatment plan is dependent upon the type, site and stage of the cancer. It must also take into consideration the personal preferences of the individual with the cancer diagnosis. Delivering these interventions takes a team of healthcare providers and often involves a complex coordination of appointments, medications, services and other supportive resources for the person with cancer and his/her caregivers. Diagnosis of cancer for the Fond du Lac community member takes place at off-reservation healthcare organizations, often far from the person's home and community. Cancer treatment for the Fond du Lac community member is further complicated because cancer is often diagnosed at a later stage when treatment is much more extensive and risk for death is greater.

Barriers faced by Fond du Lac community members with cancer include access to timely treatment; financial concerns; lack of support and supportive resources; lack of knowledge about cancer treatments and clinical trials; lack of communication between providers, the person with cancer and caregivers; and challenges in navigating the cancer care system. Another challenge is the lack of ready access to a Traditional Healer.

Designing interventions to overcome these barriers is the major focus of this section. The partnership of the person with cancer, the healthcare providers, the caregivers and an integrated cancer care system can change the outcome from one of despair to compassion and support.

Implementation

Goal:

Assess the needs of Fond du Lac community members diagnosed with cancer and Fond du Lac's capacity for providing quality cancer follow-up treatment and services, and identify gaps in these services. Develop programs and protocols to assure timely access to supportive services by community members with cancer.

Objective 1:

Ensure that Fond du Lac Healthcare providers are aware of and follow the most current clinical guidelines for cancer treatment and care.

Strategies:

1. Arrange for continuing professional education for Fond du Lac Healthcare providers regarding current clinical guidelines for cancer treatment and care.
2. Establish treatment guidelines and policies and procedures for Fond du Lac Healthcare providers to follow when providing services to people with cancer.
3. Establish ready access to current professional cancer treatment and care resources and information.
4. Provide education within the Fond du Lac community about using the Fond du Lac Healthcare providers as a resource when making decisions about cancer treatment and care.

Expected Outcome:

Consistent and state-of-the-art cancer treatment and care are available for community members with cancer.

Objective 2:

Increase awareness among Fond du Lac Healthcare providers about the benefits and protocols for effective management of the side effects of cancer treatment.

Strategies:

1. Provide continuing education for Fond du Lac Healthcare staff in recognizing and managing cancer treatment related side effects including pain, nausea, vomiting, fatigue, weight loss and loss of appetite.
2. Develop policies and procedures for Fond du Lac Healthcare staff to follow related to managing cancer patients and their treatment.
3. Increase the medications available through the Fond du Lac Pharmacy formulary to assist in managing cancer treatment side effects.
4. Offer additional healthcare services, such as massage therapy, through the Fond du Lac Human Services Division to Fond du Lac community members with cancer.

Expected Outcome:

Increased access to effective treatments to manage cancer treatment side effects by Fond du Lac community members undergoing active cancer treatment.

Objective 3:

Ensure that culturally specific, traditional healing and spiritual services are readily available to Fond du Lac community members who are diagnosed with cancer.

Strategies:

1. Provide education to increase awareness among Fond du Lac Healthcare staff of cultural traditions that may be practiced by Fond du Lac community members and how these practices may impact western medicine interventions when treating and managing cancer.
2. Actively engage Traditional Healers in provision of healthcare and spiritual support services for Fond du Lac community members with cancer.
3. Increase awareness within Fond du Lac community that Traditional Healers are available and provide information on how to access them.
4. Develop a system to facilitate easy access to Traditional Healers when a Fond du Lac community member with cancer requests this service.

Expected Outcome:

Holistic, culturally specific cancer care will be available to Fond du Lac community members.

Objective 4:

Ensure continuity of care between off-site cancer healthcare providers and Fond du Lac Healthcare providers for Fond du Lac community members with cancer.

Strategies:

1. Provide education for both Fond du Lac Healthcare providers and community members on the importance of continuity in follow-up care for cancer.
2. Establish a communication system between Fond du Lac Healthcare providers and off-site cancer healthcare providers.
3. Explore ways to utilize Fond du Lac's medical clinics computerized NextGen Client Medical Record System to improve communication and continuity of care for cancer patients.
4. Expand Fond du Lac Human Services Division's Public Health Nursing staff to include a Public Health Nurse Cancer Case Manager.
5. Expand Fond du Lac Human Services Division's Clinic staff to include a Registered Nurse specializing in cancer care.

Expected Outcome:

Fond du Lac community members with cancer receive timely, coordinated, high quality cancer care.

Objective 5:

Provide direct support services through the Fond du Lac Human Services Division programs for Fond du Lac community members with cancer.

Strategies:

1. Increase capacity for direct care services thorough a Public Health Nurse Cancer Case Manager, Community Health Worker Cancer Navigator, Clinic Registered Nurse and Adult Health Benefits Specialist or Medical Social Worker specialized in cancer care.
2. Improve Fond du Lac Human Service Division's internal Client Referral System to ensure all Fond du Lac community members with cancer have supportive services offered to them.
3. Partner with the Minnesota Cancer Alliance Navigator Task Force project to develop the Community Health Worker education course with additional training in Cancer Navigation.
4. Partner with the Fond du Lac Tribal and Community College to offer the Community Health Worker course.

Expected Outcome:

Increased numbers of qualified direct care staff to assist Fond du Lac community members with cancer.

Objective 6:

Eliminate barriers to accessing quality cancer treatment and care.

Strategies:

1. Provide education for Fond du Lac Human Services Division Social Services and Financial Services staff regarding resources available to assist with financial, transportation and treatment supplies issues for people with cancer.
2. Expand staff capacity to provide the intensive social services needed when a community member with cancer presents with financial, transportation and treatment supplies issues.
3. Develop a culturally specific brochure to educate the Fond du Lac community about Fond du Lac and off-site resources available to assist with financial, transportation and treatment supplies issues related cancer treatment and care.
4. Partner with American Cancer Society Navigator program to expand resources available to assist Fond du Lac community members with cancer.
5. Partner with local healthcare organizations to address barrier issues for Fond du Lac community members diagnosed with cancer.
6. Partner with the American Cancer Society to develop a Volunteer Driver program within the Fond du Lac community to assist in providing transportation for cancer treatment and health care appointments.
7. Provide Handicap Parking Stickers, accessed through Fond du Lac Medical Social Services, for community members who are undergoing cancer treatment.

8. Develop culturally specific literature to distribute throughout the Fond du Lac community describing resources to address barriers to accessing cancer treatment and care.
9. Provide web links to appropriate cancer information resources through the Public Health Nursing Department web page.
10. Continue to serve on the Minnesota Cancer Alliance Steering Committee to partner to address health disparity issues related to cancer faced by American Indians in Minnesota.
11. Develop partnerships with other Minnesota Tribes to explore ways to eliminate barriers to timely, high-quality cancer care for tribal populations.

Expected Outcome:

Resources are readily available for Fond du Lac community members with cancer to address barriers to cancer treatment and care.

Objective 7:

Ensure culturally appropriate, supportive counseling services are available for Fond du Lac community members with cancer.

Strategies:

1. Develop comprehensive, culturally appropriate, supportive cancer counseling services within the Fond du Lac Human Services Division Behavioral Health Department.
2. Provide education within the Fond du Lac community about the value and availability of counseling services for Fond du Lac community members with cancer.

3. Provide continuing education for Fond du Lac Human Services Division staff related to aspects of supportive counseling when working with people with cancer.

Expected Outcome:

Counseling services are readily available and appropriate for Fond du Lac community members with cancer.

Objective 8:

Increase the knowledge of and participation in cancer related clinical trials by Fond du Lac community members who have cancer or are at high risk of cancer.

Strategies:

1. Provide education opportunities for both the Fond du Lac community and the Fond du Lac healthcare providers about cancer clinical trials and the importance of these clinical trials to advancing cancer treatments and survival.
2. Assess the Fond du Lac community's perception of clinical trials through the Biennial Needs assessment survey.
3. Develop culturally specific education programs and literature for the Fond du Lac community dispelling myths about clinical trials.
4. Provide access to and educate the Fond du Lac community about the Native American Cancer Research Web site for clinical trial information that is culturally specific to American Indian people.
5. Ensure Fond du Lac community members receive information about clinical trials and support in accessing appropriate clinical trials from Fond du Lac Healthcare and Social Services staff.

6. Partner with regional and state Cancer Centers to increase education, outreach and recruitment of American Indian people, including individuals from the Fond du Lac community, into appropriate clinical trials.
7. Partner with the Native American Cancer Research organization to further the work in advancing clinical trials education and participation in clinical trials among American Indians, including individuals from the Fond du Lac community.

Expected Outcome:

Increase in knowledge about and participation in clinical trials by Fond du Lac community members.

SECTION V:

WIIDOOKAAGE CARE

FROM DIAGNOSIS AND BEYOND:

PALLIATIVE AND END-OF-LIFE CARE

Introduction

The Fond du Lac Comprehensive Cancer Team defines palliative care as “supportive interventions that begin at the moment a person receives the diagnosis of cancer.” This concept is embodied in the Ojibwe word, “Wiidookaage,” meaning “they help each other.” As the person with cancer and his/her caregivers are surrounded by knowledgeable and compassionate healthcare providers, supportive services, and a caring community, the journey through cancer is lightened. Healthcare providers are challenged to provide integrated family orientated cancer care supporting the medical and socio-emotional needs of the person with cancer and the caregivers (Journal of Chronic Disease, 1970).

Palliative care represents an issue of emerging importance in Indian Country. This is a direct result of demographic changes, including an ever-expanding elder population, increasing numbers of individuals afflicted with chronic disease, and advances in chronic disease management. Palliative care issues have rarely been addressed in Native American communities for reasons unknown. Programs for Native American communities must be culturally sensitive and readily available within the individual’s community. Foremost is the need to develop effective pain management programs, as well as those directed towards advanced care planning,

staff support, and respite care. Building infrastructure to meet this need is most important and includes training for clinicians, caregivers, and patients in methods currently available to relieve human suffering. (Michalek, Mahoney, Gilbert, Kaur, 2005)

The Fond du Lac Wiidookaage Cancer Plan contains several strategies to begin to address the needs for palliative care whether the care supports the person with cancer into his/her Spirit Journey or leads to long-term survivorship.

Implementation

Goal:

Provide culturally specific, comprehensive, supportive health and social services to all Fond du Lac community members who are diagnosed with cancer.

Objective 1:

By June 2008, develop and implement a system for identifying and tracking all Fond du Lac community members diagnosed with cancer.

Strategies:

1. Develop a collaborative tracking system between the departments of the Fond du Lac Human Services Division focused on clients with a cancer diagnosis.
2. Clarify current Fond du Lac Human Services interdepartmental referral system to assist in tracking of Fond du Lac community members with cancer diagnosis.
3. Define documentation procedures for all Fond du Lac Human Services departments providing services for Fond du Lac community members with cancer diagnosis.

Expected Outcome:

Fond du Lac community members with cancer are identified and a tracking system enabled to better aid Fond du Lac Human Services Division staff to offer comprehensive cancer care support.

Objective 2:

Provide culturally specific, integrated, family-orientated cancer care and education supporting the medical and socio-emotional needs of the Fond du Lac community members with cancer and their caregivers.

Strategies:

1. Enhance Fond du Lac Human Services Division staff to provide supportive palliative care for Fond du Lac community members with cancer and their caregivers including, but not limited to:
 - Public Health Nurse Cancer Case Manager
 - Community Health Worker Cancer Navigator
 - Medical Social Worker with cancer services focus.
 - Behavioral Health Clinic Counselor with cancer counseling focus.
2. Provide specialized educational opportunities for Fond du Lac Human Services staff involved with Fond du Lac community members with cancer and their caregivers.
3. Form a Task Force to assess current supportive services and develop culturally specific support services for Fond du Lac community members with cancer and their caregivers.

4. Collaborate with local, regional and national cancer partners to provide supportive resources for Fond du Lac community members with cancer and their caregivers throughout the cancer journey.
5. Provide culturally specific education to Fond du Lac community members with cancer and their caregivers about the cancer support services that are available through the Fond du Lac Human Services Division.
6. Ensure that Fond du Lac community members with cancer and their caregivers have access to Traditional Healers and Spiritual Guides.

Expected Outcome:

Comprehensive, culturally appropriate support services are readily available for Fond du Lac community members with cancer and their caregivers.

End-of-Life Care

Objective 3:

Educate Fond du Lac Healthcare providers and the Fond du Lac community about the need for and the benefits of end-of-life care.

Strategies:

1. Partner with local Hospice Services to provide training in end-of-life cancer care for Fond du Lac healthcare staff.
2. Form a Cancer Care Team within the Fond du Lac Human Services Division to assess, identify and provide end-of-life care to Fond du Lac community members with cancer who are in need of this service.

3. Provide education within the Fond du Lac community about end-of-life cancer care and know how to access these services.

Expected Outcome:

Fond du Lac community members will be aware of supportive end-of-life services and how to access them.

Objective 5:

Increase awareness of, and access to, comprehensive pain assessment and pain management provided by Fond du Lac healthcare providers for Fond du Lac community members with cancer, especially with end-of-life cares.

Strategies:

1. Provide education opportunities for Fond du Lac healthcare providers regarding appropriate pain assessment and management.
2. Ensure the Fond du Lac Pharmacy has appropriate pain management medications readily available when pain medications are prescribed for a Fond du Lac community member with cancer.
3. Partner with local Hospice Services to maximize supportive services for end-of life care for Fond du Lac community members with cancer who are receiving these services, especially in the area of pain management.

Expected Outcome:

Fond du Lac community members experiencing cancer related pain will have effective pain relief interventions.

Objective 6:

Increase awareness of end-of-life issues for Fond du Lac community members with cancer and their caregivers.

Strategies:

1. Provide educational opportunities within the Fond du Lac community to increase awareness of treatments and services available for end-of-life supportive cares.
2. Provide education within the Fond du Lac community related to cancer pain management.
3. Inform the Fond du Lac community of services and resources available to support a Fond du Lac community member with cancer in need of end-of-life care.
4. Provide education within the Fond du Lac community related to culturally specific end-of-life care.
5. Provide web links to appropriate cancer information regarding end-of-life issues resources through the Fond du Lac Human Services Division's Public Health Nursing Department web page.

Expected Outcome:

Fond du Lac community members are aware of the issues surrounding end-of-life care, treatments and services available for Fond du Lac community members and their caregivers related to end-of-life care.

Objective 7:

Enhance palliative care and end-of-life services for Fond du Lac community members and their caregivers through community volunteers.

Strategies:

1. Partner with local Hospice services to train interested Fond du Lac community members to become Hospice Volunteers.
2. Develop a program within the Fond du Lac Human Services Division to coordinate Hospice Volunteer services.

Expected Outcome:

Culturally specific Hospice Volunteer services are available and utilized within the Fond du Lac community.

Objective 8:

Support the Fond du Lac community member with cancer through an individualized nursing care plan.

Strategies:

1. Provide comprehensive case management services for Fond du Lac community members through the Fond du Lac Public Health Nursing Department.
2. Partner with local Hospice Services to augment their services when a Fond du Lac community member is receiving Hospice Services.

Expected Outcome:

Fond du Lac community members with cancer have ready access to individualized, supportive end-of-life care.

Objective 9:

Eliminate financial barriers to accessing quality end-of-life care for Fond du Lac community members with cancer.

Strategy:

1. Provide information and resources for financial support services through the Fond du Lac Human Services Social Services Medical Social Worker Adult Disability Specialist.

Expected Outcome:

Financial barriers to quality end-of-life care are eliminated for Fond du Lac community members with end-stage cancer.

SECTION VI:

SURVIVORSHIP

Introduction

Recent advances in the prevention, early detection, diagnosis, and treatment of cancer help cancer patients live longer. As a result, the number of cancer survivors is increasing. There is recognition of the complications of both cancer and its treatment, and the resulting physical, social and mental challenges encountered by survivors over the near and long terms following a cancer diagnosis and the practical daily living issues of living with cancer. As of January 2000, there were approximately 9.8 million cancer survivors in the United States. (National Cancer Institute, 2006) An initial step in improving the care of cancer survivors is to raise awareness and provide information in the health care community, among cancer survivors, and the general public. As individuals make the transition from cancer patient to cancer survivor, they need to be informed about the long-term effects so they can be active partners in their own long-term care. (Lewis, 2006)

Components of an Effective Program for Long-Term Cancer Survivors

- Consideration of long-term issues and survivorship from the time of diagnosis.
- A multidisciplinary approach, including participation by a nurse who can synthesize medical information, target education, and create a health promotion focus.
- A treatment plan that
 - Documents treatment received (including dosages) and future health risks from treatment.
 - Has a wellness focus (including exercise and nutrition), which patients can take with them and share with whomever is following them, whether an oncologist or primary care provider.
- A comprehensive database, for use in both for research and in identifying survivor issues.
- Education of nurses, other health care providers, and program staff about survivorship issues and resources available within the community.
- Education of survivors and their families about long-term issues.
- Involvement of survivors in planning initiatives of the program.
- Creation of a community of survivors, including a virtual or Web-based community, where they can share information.
- Involvement of the local community, both for support services and for financial backing.

(Lewis, 2006)

Implementation

Goal:

Enhance the quality of life for all Fond du Lac community cancer survivors through quality services and programs for cancer survivors.

Objective 1:

Conduct assessment with Fond du Lac cancer survivors to determine their needs by December 2008.

Strategies:

1. Conduct Focus Groups with Fond du Lac community cancer survivors to gather information about their needs.
2. Utilize the Fond du Lac Biennial Needs Assessment Survey as a tool to gather information regarding the needs of community cancer survivors.
3. Partner with the Spirit of Eagles Program and the University of Wisconsin Comprehensive Cancer Center to conduct a Quality of Cancer Care: The Cancer Survivors' Voice community participatory research project within the Fond du Lac community to follow pilot research conducted during 2005 through Northern Arizona University and the University of Arizona.
4. Conduct one-to-one interviews with Fond du Lac community cancer survivors to gather information about his/her perceived needs.
5. Form a Task Force including Fond du Lac community members and Fond du Lac Health and Social Services staff to develop programs based on results of assessment.

Expected Outcome:

Programs are developed and implemented that are culturally specific and based on the needs identified by the Fond du Lac community cancer survivors.

Objective 2:

Provide supportive interventions for Fond du Lac community cancer survivors.

Strategies:

1. Organize and facilitate cancer survivor support groups for Fond du Lac community cancer survivors.
2. Provide counseling services for cancer survivors through the Fond du Lac Human Services Behavioral Health Department.
3. Provide community outreach/cancer navigator services to assist Fond du Lac community cancer survivors locate and access supportive resources.
4. Partner with other cancer focused agencies/organizations such as the American Cancer Society, Lance Armstrong Foundation, Susan B. Koman Foundation, Avon, etc. that offer cancer survivor programs and resources in increased access to supportive services for Fond du Lac community cancer survivors.
5. Collaborate with the Native American Cancer Survivors Network to expand their outreach within the Fond du Lac community.

Expected Outcome:

Increased programming and supportive services for Fond du Lac community cancer survivors.

Objective 3:

Remove financial and post-cancer diagnosis supplies issues as a barrier to optimal survivorship for Fond du Lac community cancer survivors.

Strategies:

1. Enhance Fond du Lac Social Services programs to include services and counseling to assist Fond du Lac community cancer survivors with financial and post-cancer diagnosis supplies (example: breast prosthesis) issues related to cancer.
2. Provide assistance to Fond du Lac community cancer survivors with obtaining post-cancer diagnosis supplies through a community outreach/cancer navigator services.
3. Provide education within the Fond du Lac community about resources available to assist with financial needs related to cancer.

Expected Outcome:

Financial barriers are removed for Fond du Lac community cancer survivors.

Objective 4:

Address long-term needs of cancer survivors within the Fond du Lac community.

Strategies:

1. Assess long-term needs of Fond du Lac community cancer survivors.
2. Utilize the findings from the Cancer, Employment and American Indians pilot research conducted during 2005 through Northern Arizona University and the University of Arizona in the assessment and planning process.

3. Develop programs to address the long-term needs of Fond du Lac community cancer survivors based on assessment results.
4. Facilitate referrals to Rehabilitation Services provided through the Minnesota Chippewa Tribe for cancer survivors who may benefit from this service.
5. Implement policy and procedures to assist community cancer survivors who are employed within Fond du Lac Reservation enterprises.

Expected Outcome:

Cancer survivors within the Fond du Lac community are empowered to remain vibrant, productive members within the community.

Objective 5:

Increase awareness of issues specific to cancer survivors among Fond du Lac Human Services Division Health and Social Services care providers.

Strategies:

1. Collaborate with Cancer Partners from local, regional, state, federal organizations/agencies and from within Indian Country to provide education opportunities for Fond du Lac Human Services Division staff about cancer survivorship issues.
2. Assist Fond du Lac community cancer survivors to communicate their needs to health and social services care providers within Fond du Lac and to off-site agencies and resource providers.

Expected Outcome:

Improved communication between Fond du Lac community cancer survivors and health and social services care providers.

Objective 6:

Increase awareness within the Fond du Lac community about issues and resources available to support Fond du Lac community cancer survivors.

Strategies:

1. Provide education within the Fond du Lac community about issues and resources available for Fond du Lac community cancer survivors.
2. Develop a Cancer Survivors resource section within the Fond du Lac Reservation community library.
3. Provide web links to appropriate cancer information resources through the Public Health Nursing Department web page for the Fond du Lac Reservation Web Site.

Expected Outcome:

Fond du Lac community members are aware of the issues and resources for community cancer survivors.

Objective 7:

Mobilize Fond du Lac community cancer survivors to employ their collective experience and wisdom to enhance the quality of life for all cancer survivors within the Fond du Lac community.

Strategies:

1. Collaborate with American Cancer Society in the development of volunteer services opportunities for Fond du Lac community cancer survivors.
2. Seek funding resources from Cancer Partners to support the development of volunteer services opportunities for cancer survivors.
3. Ensure representation by community cancer survivors on the Fond du Lac Cancer Team.
4. Encourage and support Fond du Lac community cancer survivors in sharing their stories through a variety of venues both locally and throughout Indian Country.
5. Continue serving on the Minnesota Cancer Alliance Steering committee and its' Task Forces to develop opportunities for cancer survivors from American Indian communities.
6. Provide leadership in developing the volunteer opportunities for Fond du Lac community cancer survivors through the Fond du Lac Human Services Division.
7. Continue to support and expand cancer volunteer activities currently in place within the Fond du Lac community such as the Wiidookaage Relay for Life team that has been a major mobilizing factor in removing barriers from discussing cancer.

Expected Outcome:

Fond du Lac community cancer survivors are actively engaged in programs and services related to cancer issues.

SECTION VII:

CAREGIVERS

Introduction

While the impact of a cancer diagnosis on the lives of family members is recognized, there remains a need for family-based intervention. The role of the family in providing support/caregiving to a relative with cancer is recognized as a biopsychosocial process. It is important to note that as Messner reported: “Many patients [and their families] do not have access to state-of-the-art treatment and supportive care therapies due to the following barriers: cost, travel logistics, fatigue, misinformation, rural isolation, geography, language, low literacy and comprehension, ”yet, according to Ell and Northen (1990) the “vital role” of family in “health promotion, health maintenance, and in the management of illness” (p. 13) is acknowledged, leaving service providers to understand that that must insure the barriers to state-of-the art treatment must be removed in order for caregivers to best assist their loved ones.

A number of researchers have pointed out that family support is not only multifaceted, but also sustained across the lifespan of the person with chronic illness/disability, and thus must be included in research regarding disability-related issues. The family’s committed lifespan role contrasts with the role played by most health professionals and service providers, including rehabilitation counselors, who typically offer focused attention on a time-limited basis. Speice, et al. reported “family members serve as a resource for patients making critical decisions about treatment. They may affirm or challenge decisions about a treatment protocol. Sometimes they even have to prompt the patient to get treatment” (p. 106).

Implementation

Goal:

Assess the needs of and identify gaps in services for Fond du Lac community members who are caregivers for people with cancer. Develop services and programs for caregiver support.

Objective 1:

Assess the Fond du Lac community members who are or have been cancer caregivers.

Strategies:

1. Develop methods and tools to gather information from Fond du Lac community members who are or have been, cancer caregivers.
2. Utilize findings from the Cancer, Employment and American Indians pilot research conducted during 2005 through Northern Arizona University and the University of Arizona research project as part of the assessment process.
3. Continue to gather information regarding caregiving aspects and issues through literature searches about caregiving and networking with other organizations focused on cancer issues.
4. Form a Task Force including Fond du Lac community members who are or have been cancer caregivers and staff from the Fond du Lac Human Services Division to develop services and programs for cancer caregiving.

Expected Outcome:

Assessment is completed and results are used to develop interventions for Fond du Lac community members who are cancer caregivers.

Objective 2:

Provide support services through the Fond du Lac Human Services Division for Fond du Lac community members who are cancer caregivers.

Strategies:

1. Develop and facilitate support group for caregivers and families of persons with cancer
2. Provide counseling Services through MNAW Behavioral Health Department
3. Provide support Services through MNAW Medical Social Services and MNAW Public Health Nursing Department
4. Provide respite services for caregivers
5. Engage volunteers in supporting caregivers.

Expected Outcome:

Fond du Lac community members who are caretakers for persons with cancer will receive support from medical and social service professionals and community members.

Objective 3:

Provide culturally specific education and resources for Fond du Lac community members who are cancer caregivers.

Strategies:

1. Caregivers' Resource Information Center will be established in library at Tribal Center
2. Caregivers/families of person with cancer diagnosis will be offered specific education on cancer

3. Provide web links to appropriate cancer information resources through the Public Health Nursing Department web page for the Fond du Lac Reservation Web Site

Expected Outcome:

Caretakers for persons with cancer have access to relevant cancer information.

A CAREGIVER'S STORY

My younger sister Nada K. Joseph was diagnosed with Stage IV breast cancer in 1997—she fought the demon until she no longer could and walked on in 1999. I made a promise to her that I would continue her fight until my last breath.

We have a large family (nine children) and I was closest to her. Not only was she a member of the Fond du Lac Band of Lake Superior Chippewa but she was also a member of the Lesbian/Gay community. She was an athlete, a nonsmoker who took care of herself, and I believe an experience of this magnitude is even more difficult knowing you've always been "healthy."

She asked me to help—to become her caregiver and I was, and am honored. First of all most of us really know so little about this "demon" except we immediately think of death. I jumped in and began to do my own research. The medical jargon alone is overwhelming and because there is no "cure" for cancer, I observed many of her health care providers debate over which treatment plan would be the best and then leave it up to her. While we were actively involved in her health care decisions, this aspect of her journey was probably the most frustrating. All treatments and protocols were gut wrenching decisions.

This experience is almost indescribable but think of every verb that describes sadness, helplessness and any other emotionally crippling pain—that is how a caregiver feels. To navigate through the "unknown" is scary enough but to know deep in your heart and soul that Stage IV patients rarely survive never leaves your thoughts.

There is no magic answer as to what is right or wrong in caring for a cancer patient. Most of the time I felt paralyzed but somehow I had to step up to the plate and offer her what help I could. One really has to keep an open mind and heart throughout the journey for there will actually be good days as well as those bad days that rear their ugly heads. The hardest for me was to not take things personally. My sister, like so many who are fighting this disease, would have days of anger and rage, days of total silence, days of great hope and days of little hope, days of joy and far too many days and nights of unpredictability.

Most everyone had incredibly high expectations of her—I suppose because she was such a gregarious and healthy person. It was difficult for them to see her in a weakened state but these daily expectations took their toll on her very quickly as she felt it was her duty to "counsel" everyone who was feeling bad. That exhausted her and one day she said to me, "Don't they realize I'm fighting for my life?" It was then that I had to change her daily schedule and "thin the herd" as we called it. I put a voice mail message on the telephone offering a daily update and that most often she was resting and unable to come

to the phone. I screened all visitors, including family members, which was perceived as "being shut out." All of her energy had to focus on the battle.

Even though she had a bone marrow (stem cell) transplant she was never totally cancer free and had three recurrences. When she first called to tell me I was packed and in the car in 15 minutes. Five hours later I walked into her kitchen and she was wearing this sleeveless white tee shirt. That "lump" drew me directly to it but I refused to allow it to disrupt our usual greeting of hugs and kisses. My sister then took my hand and placed it on the evil spot and I was shocked and felt sick to my stomach as I tried to maneuver it around, but it wouldn't budge! Huge as a grapefruit and hard as a rock. Because I had lost eight close friends and colleagues to breast cancer in the passed three years, I had some familiarity with the "stages" but this scared the daylights out of me. When the biopsy was done and the syringe produced no liquid from the area my heart sank. I knew then that she was terminal. I never spoke those words out loud to anyone and this is the first time I've publicly stated this.

Early detection is KEY! Mammograms and breast self-examinations can save your life. My sister knew she waited too long to go in . . . she only told me that once during her two year struggle. At that time we couldn't find any American Indian support group much less any resources in the Lesbian community. There is a huge need for support in all forms that is culturally appropriate for our people including two spirited people.

When she had her stem cell transplant at Karmonos Hospital on the Wayne State University Campus in Detroit, she was the first American Indian person to ever participate in that program. The head of the program was so intrigued he came to visit Nada often, which we were told was rare. He eventually asked me to ask Nada if she would be interested in being interviewed by all three local television stations (NBC, CBS and ABC). The interviews not only focused on her cancer but on the importance and impact her cultural beliefs and traditions had on her as she prepared for battle each day, and then finally as she prepared for her spiritual journey.

Bonnie Wallace, Giidaagahbinesikwe (Spotted Eagle Woman)

SECTION VIII:

EVALUATION

Introduction

Evaluation, a systematic process of determining the extent to which a program and its components function, is essential to providing programmatic direction, demonstrating the use of resources and indicating the need for program revisions and improvements. Evaluation processes also serve to identify strengths and weaknesses in the program and its components and the information gathered from evaluation helps refine the program, which ultimately produces increasingly successful outcomes. Additionally, regular, systematic, and accurate assessment of the program and timely reporting of evaluation findings is important to the sustainability of the program.

The Centers for Disease Control and Prevention (1999) developed a framework for public health evaluation involving six interdependent steps to be utilized in evaluating a program. Application of this framework allows for the planning of effective public health strategies, including a focus on program improvements and demonstrating the results of the program. Similarly, each Building Block for Comprehensive Cancer Control integrates evaluation components that FDL has followed throughout the planning process and will continue to follow as the plan is implemented. FDL's evaluation activities will be based on the evaluation framework depicted on the next page and in coordination with the Building Blocks.

The steps within this framework compose the steps that should be taken in any public health program evaluation and assist in answering questions such as:

- *What will we evaluate?*
- *What criteria will we use to critique program performance?*
- *Who are our primary intended users and stakeholders?*
- *How will we use our evaluation findings?*
- *To what extent are our goals and objectives being met?*
- *How well is our program functioning?*
- *What resources do we need to assist us with our evaluation efforts?*

In addition, the model includes a set of standards to govern the evaluation activities. These standards were adopted by the Joint Committee on Standards for Educational Evaluation and incorporated into this framework to provide the criteria by which to judge the quality of program evaluation efforts. Incorporating this framework into our evaluation plan and utilizing its methods will allow us to answer key questions about the direction and effectiveness of Fond du Lac's (FDL) Comprehensive Cancer Control Program.

An example of FDL's incorporation of this framework into our evaluation plan includes sharing the results of program/activities evaluations with the Fond du Lac Cancer Team on an annual basis. At the same time, results are reported to the Fond du Lac Human Services Division's Main Continuous Quality Improvement (CQI) Committee. The Main CQI Committee monitors the progress of the Cancer Program and its members provide input to the FDL Cancer Team with recommendations for changes and improvements. Sharing of results will assist in making informed decisions based on evidence obtained from the evaluation.

Additionally, as we move forward in our evaluation process, we recognize that the first step of the framework, engaging stakeholders is essential to our success. While we have engaged stakeholders, we also recognize the value of engaging additional internal and external resources and support to move our evaluation efforts forward. By maximizing our resources, we are confident that a solid evaluation plan will be developed.

Knowing that this framework is non-prescriptive, yet participatory in nature, we believe that the implementation of this framework will provide the starting points around which FDL can tailor an evaluation to best meet our needs. While we recognize that each step is mutually supporting of the other and prior steps provide the foundation for future progress, it also is a model that allows for sensitivity to our programs unique aspects and context. We are confident that this model will allow us to focus our efforts to promote capacity building, mobilize the community, develop and maintain partnerships, instill program integration and coordination and the sharing and monitoring of resources for planning, implementation and evaluation.

Goal:

Establish a systematic evaluation plan to monitor the progress of Fond du Lac's Comprehensive Cancer Plan activities.

Objective 1:

Institute an evaluation structure following components of the CDC Framework for Public Health Evaluation and the Building Blocks for Comprehensive Cancer Control, by December 31, 2008.

Strategies:

1. Assemble an evaluation team by identifying internal and external resources and staff for evaluation.

2. Engage stakeholders and describe the context of the program and how it fits into the larger organization and community.
3. Design the evaluation, the users, the uses for the evaluation, stakeholder interests, evaluation questions, methods, timeline, systems for monitoring, tracking, and documenting implementation activities and sharing of results.
4. Gather, analyze, and interpret data.
5. Justify conclusions in conjunction with stakeholders and evaluation team.
6. Report on conclusions.

Expected Outcomes:

The Fond du Lac Comprehensive Cancer Program will have an ongoing evaluation program to guide program progress.

Objective 2:

Evaluation of Fond du Lac's Comprehensive Cancer Plan is integrated into the Fond du Lac Human Services Division's Continuous Quality Improvement (CQI) Program by Dec. 31, 2009.

Strategies:

1. Integrate monitoring and evaluation of FDL Cancer Plan into routine FDL HSD (Human Services Division) CQI activities.
2. Contract with an Evaluation Consultant to assist in development and application of an evaluation plan for comprehensive cancer programming.

Expected Outcome:

Improved evaluation of cancer control activities

Objective 2:

Measurable objectives and CQI indicators are written for each action plan created for selected strategies when Cancer Plan is implemented.

Strategies:

1. FDL Cancer Team prioritizes and selects strategies to be implemented from Wiidookaage Cancer Plan.
2. Ad Hoc Committees are formed to develop action plans with measurable objective(s) and Indicator for each action plan.
3. Achievement of action plan objectives and indicator are monitored through the FDL HSD CQI process.

Expected Outcome:

Improved evaluation of cancer control activities.

Objective 3:

Cancer screening data is monitored on an annual basis.

Strategies:

1. Utilize the Clinical Reporting System (CRS) Indicators List for National GPRA report in developing evaluation indicators for cancer screening.
2. NextGen Electronic Medical Record System is enhanced to be able to generate reports on GPRA Standard parameters for selected cancer screening data.

3. Fond du Lac Human Services Division CQI committee reviews reports on an annual basis and makes recommendations for program improvement as necessary.

Expected Outcome:

Improved evaluation of cancer control activities.

Objective 4:

Activities focused on reduction of nonceremonial tobacco use are routinely monitored.

Strategies:

1. Monitor tobacco use through the Biennial Community Needs Assessment.
2. Design a tool to assess smoking status of public areas within FDL Reservation.
Conduct survey on an annual basis to identify trends and report findings to FDL HSD CQI committee.

Expected Outcome:

Database to measure trends in nonceremonial tobacco use is established.

REFERENCES

- Alferi, S. M., Carver, C. S., Antoni, M. H., Weiss, S., & Durán, R. E. (2001). An exploratory study of social support, distress, and life disruption among low-income Hispanic women under treatment for early stage breast cancer. *Health Psychology, 20*(1) 41-46.
- American Cancer Society Midwest Division, Minnesota Cancer Alliance and Minnesota Cancer Surveillance System. *Minnesota Cancer Facts and Figures 2006*. Minneapolis, MN: American Cancer Society Midwest Division, 2006, pages 13-14.
- Baider, L., Cooper, C.L., & Kaplan De-Nour, A., (Eds.). (2000). *Cancer and the family*, 2nd ed. New York: John Wiley & Sons.
- Burhansstipanov, L., & Satter, D. E. (2000). Office of Management and Budget racial categories and implications for American Indians and Alaska Natives. *American Journal of Public Health 90*(11), 1720-1723
- Carter, P.A. (2003). Family caregivers' sleep loss and depression over time. *Cancer Nursing, 26*, 253-259.
- Centers for Disease Control and Prevention. Framework for Program Evaluation in Public Health. MMWR 1999; 48(No. RR-11).
- Centers for Disease Control and Prevention. Preventing and Controlling Cancer: The Nation's Second Leading Cause of Death 2005. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, Coordinating Center for Health Promotion. Atlanta, GA.
- Centers for Disease Control & Prevention & National Institutes of Health. *Healthy People 2010: What Are Its Goals?*. Available online at <http://www.healthypeople.gov/about/goals.htm>
- Colditz, G. A., and Stein, C. J. (2004). *Handbook of Cancer Risk Assessment and Prevention*. Boston: Jones and Bartlett Publishers
- Community Health Profile: Minnesota, Wisconsin, & Michigan Tribal Communities, 2006.
Great Lakes EpiCenter. Great Lakes Inter-Tribal Council, Inc. 2006

- Connell, C.M., & Gibson, G. D. (1997). Racial, ethnic, and cultural differences in dementia caregiving: Review and analysis. *The Gerontologist*, 37(3), 355-364.
- Edwards, B., & Clarke, V. (2004). The psychological impact of a cancer diagnosis on families: The influence of family functioning and patients' illness characteristics on depression and anxiety. *Psycho-Oncology*, 13(8), 562-576.
- Edwards, B. K., & Swan, J. C. (2001). *A National Perspective on Cancer Surveillance & Measuring Health Disparities*. National Cancer Institute presentation, Scottsdale, AZ.
- Ell, K., & Northen, H. (1990). *Families and health care*. New York: Aldine de Gruyter.
- Gotay, C. C. (2000). Culture, cancer, and the family. In L. Baider, C.L. Cooper, & A. Kaplan De-Nour (Eds.), *Cancer and the family*, 2nd ed. (pp. 95-110). New York: John Wiley & Sons.
- Government Performance Results Act (2004). *Improving the Quality of Health Care 2004 Measuring Successes and Challenges*. Indian Health Service 2004 Executive Summary.
- Hiatt, R. (2006). *Avoiding Cancer and the Best Care*. Television Presentation by University of California Television
- Hughes, D., Seidman, E., & Williams, N. (1993). Cultural phenomena and the research enterprise: Toward a culturally anchored methodology. *American Journal of Community Psychology*, 21(6), 687-703.
- Isaksen, A. S., Thuen, F., & Hanestad, B. (2003). Patients with cancer and their close relatives. *Cancer Nursing*, 26(1), 68-74.
- Journal of Chronic Disease, 1970, Vol. 22, pp. 743-755, Pergamon Press, Printed in Great Britain
- Lewis, L. (2006). Discussion and Recommendations: Addressing Barriers in the Management of Cancer Survivors. *American Journal of Nursing*, 106(3), pps. 88, 95.
- Mackay, J., Jemal, A., Lee, N. C., Parkin, D. M., (2006). *The Cancer Atlas* (p. 70). American Cancer Society: Atlanta, GA.

Marshall, C. A. (2001). Cultural factors in conducting research and ethical responsibilities in serving American Indians with disabilities (pp. 165-175). In C. A. Marshall (Ed.), *Rehabilitation and American Indians with disabilities: A handbook for administrators, practitioners, and researchers* (219-234). Athens, GA: Elliott & Fitzpatrick, Inc.

Marshall, E. S., & Crane, D. R. (2005). End note: Interdisciplinary perspectives of families and health. In D. Russell Crane, & E. S. Marshall (Eds.), *Handbook of families & health: Interdisciplinary perspectives* (pp. 467-469). Thousand Oaks: Sage Publications.

Marshall, C.A., Sanders, J. E., & Hill, C.R. (2001). Family voices in rehabilitation research. In C. A. Marshall (Ed.), *Rehabilitation and American Indians with disabilities: A handbook for administrators, practitioners, and researchers* (pp. 219-234). Athens, GA: Elliott & Fitzpatrick, Inc.

Messner, C. (2005). Innovations in cancer education: The challenge of disseminating benchmark research to the oncology population. *Journal of Cancer Education*, 20(3), S36.

Michalek, A. M., Mahoney, M. C., Gilbert, A., & Kaur, J. (2005). Palliative Care Services: A Survey of Tribal Health Directors. *The Indian Health Service Primary Care Provider* 30(5), 118-119.

Murray, L. R. (2003). Sick and tired of being sick and tired: Scientific evidence, methods, and research implications for racial and ethnic disparities in occupational health. *American Journal of Public Health*, 93(2), 221-226.

National Cancer Institute. Cancer Control and Population Sciences: Research Findings (on-line). Available at: <http://dccps.nci.nih.gov>

Northouse, L., Kershaw, T., Mood, D., & Schafenacker, A. (2005). Effects of a family intervention on the quality of life of women with recurrent breast cancer and their family caregivers. *Psycho-Oncology*, 14(6), 478-491.

Rothschild, S. K. (1992). The family with a member who has cancer. *Primary Care*, 19(4), 835-852.

Sandberg, J.G. (2005). Interventions with family caregivers. In D. Russell Crane, & E. S. Marshall (Eds.), *Handbook of families & health: Interdisciplinary perspectives* (pp. 407-422). Thousand Oaks: Sage Publications.

Schacht, R. M., White, M., Daugherty, R., LaPlante, M., & Menz, F. (2003). *An analysis of disability and employment outcome data for American Indians and Alaska Natives*. Flagstaff: Northern Arizona University, Institute for Human Development, Arizona University Center on Disabilities, American Indian Rehabilitation Research and Training Center. (Available from the American Indian Rehabilitation Research and Training Center, Institute for Human Development, Northern Arizona University, PO Box 5630,

Flagstaff, AZ 86011)

Smith, L. T. (1999). *Decolonizing Methodologies: Research and Indigenous Peoples*. London: Zed Books, Ltd.

Spelten, E.R., Sprangers , M., & Verbeek, J.H.A.M. (2002). Factors reported to influence the return to work of cancer survivors: A literature review. *Psycho-Oncology*, 11(2), 124-131.

Suinn, R. M., & VanderBos, G.R. (Eds.). (1999). *Cancer patients and their families: Readings on disease course, coping, and psychological interventions*. Washington, DC: American Psychological Association.

Turnbull, H.R., & Turnbull, A. P. (1989). Report of consensus conference on principles of family research. (Available from the University of Kansas Bureau of Child Research; Beach Center on Families and Disability; 3111 Haworth Hall; Lawrence, Kansas 66045).

When someone in your family has cancer (1995). U.S. Department of Health and Human Services, National Institutes of Health (NIH), National Cancer Institute. NIH Publication No. 04-2685.

Weihs, K., Fisher, L., & Baird, M. (2002) Families and the management of chronic disease. Report for the Committee on Health and Behavior: Research Practice and Policy; Institute of Medicine, National Academy of Sciences. *Families, Systems and Health*, 20(1), 7 – 46.

Yates, Y. (1999). Family coping: Issues and challenges for cancer nursing. *Cancer Nursing*, 22(1), 63-71.

ACKNOWLEDGEMENTS

Jewell Anderson, RN
Health Benefits Specialist
Fond du Lac Social Services Department

Chris Berini
Fond du Lac Community Member

Marva Bohen, MS, RN
Director, Outreach and Education
University of MN Cancer Center

Colleen Carlson, CRDA
Fond du Lac Dental Department

Angelique Coffey
Medical Social Worker
Fond du Lac Social Services

Chris Davis, RN
Elder Care
Fond du Lac Public Health Nursing Department

Joycelyn Dorscher, MD
Director
Center of American Indian and Minority Health
University of Minnesota – Duluth Medical School

Karen DuFault
Lead Community Health Representative
Fond du Lac Public Health Nursing Department

Patricia Ells
Fond du Lac Community Member

DeAnna Finifrock, RN, PHN, MSN
Comprehensive Cancer Grant Manager
Fond du Lac Public Health Nursing Department

Catherine A. Marshall, Ph.D., CRC
Research Professor
Northern Arizona University

Jim McLean RN, MSN
Program Coordinator
Sage Screening Program
Minnesota Department of Health

Kristi Melby, RPh, PharmD
Clinical Pharmacist
Fond du Lac Pharmacy Department

Phil Norrgard, M.S.W.
Director
Fond du Lac Human Services Division

Debra Rissanen, LPN, C.Ped
Fond du Lac
Min No Aya Win Human Services Clinic

Nate Sandman, BAS
Lead Health Educator
Fond du Lac Public Health Nursing Department

Janette Setterquist, RN
Evaluation and Accreditation Coordinator
Fond du Lac Human Services Division

David Smith
Fond du Lac Community Member

Debra M. Smith, RN, PHN, MSN
Public Health Nursing Coordinator
Fond du Lac Public Health Nursing Department

Rollin Smith
Fond du Lac Community Member

Marilyn Grover
Fond du Lac Community Member

Julia (Bunny) Jaakola MSW
Program Development Coordinator
Fond du Lac Human Services

Wendy Janke, RN
Fond du Lac Medical Clinic and
Fond du Lac Community Member

Marjorie Johnson, BA Communications
Health Promotions Coordinator
American Cancer Society

Sharon R. Johnson, M.S., CRC
Community Member
Fond du Lac Reservation

Charles Kendall, MD
Chief Medical Officer
Fond du Lac Medical Clinics

Dannell Kettelhut
FDL Employee Benefit Supervisor
Fond du Lac Insurance Company Board

Debra Susienka
FDL Cancer Program Outreach Worker
Fond du Lac Public Health Nursing Department

Dara Topping
Fond du Lac Community Member

Debra Topping
Fond du Lac Community Member

Ruth Towslee
Fond du Lac Community Member

Bonnie Wallace, Giidaagahbinesikwe
(Spotted Eagle Woman)
Fond du Lac Community Member

Kevin Walsh R.PA-C, M.S.W.
Clinic Coordinator
Fond du Lac Medical Clinic

Chuck Walt
Associate Director
Fond du Lac Human Services Division

FOND DU LAC CANCER PROGRAM PARTNERS

American Cancer Society
Duluth, MN Office

American Cancer Society
Minnesota Region
Midwest Division

Center for American Indian and Minority
Health, Medical School
University of Minnesota- Duluth, MN

Centers for Disease Control: Cancer Branch
Atlanta, Georgia

Circle of Life Home Health
Duluth, MN

Dialogue for Action: Colorectal Cancer in
American Indians in Minnesota Intertribal
Council

Duluth Clinic Cancer Center
Duluth, MN

Fond du Lac Band of Lake Superior Chippewa
Enrolled Members and Community

Fond du Lac Human Services Division
Advisory Board
Fond du Lac Reservation, MN

Fond du Lac Insurance Board
Fond du Lac Reservation, MN

Fond du Lac Reservation Business Committee
(Tribal Council)

Fond du Lac Reservation Human Services

Cancer Information Service
Madison, Wisconsin

Great Lakes Inter-Tribal Epi Center
Lac du Flambeau, Wisconsin

SAGE: Minnesota Breast and Cervical Cancer
Screening Program
St. Paul, Minnesota

Catherine Marshall, Ph.D.
Northern Arizona University
Tucson, Arizona and Flagstaff, Arizona

Carlos Gallego
Intercultural Cancer Council (ICC)
Chaska, Minnesota

Cancer Information Service
Rochester, Minnesota

Linda Burnhansstipov, Ph.D.
Native American Cancer Education for
Survivors,
Native American Cancer Research
Pine, Colorado

Minnesota Cancer Surveillance System
Minneapolis, Minnesota

Spirit of EAGLES
Rochester, Minnesota

Minnesota Cancer Alliance
St. Paul, Minnesota

Mayo Clinic Cancer Center
Rochester, Minnesota

Mayo Clinic Native Programs

Division Staff

Shakopee Mdewakanton Sioux
Community Wellness
Prior Lake, Minnesota

St. Mary's/Duluth Clinic Breast Center and
St. Mary's Hospice
Duluth, Minnesota

University of Minnesota Cancer Center
Minneapolis, Minnesota

YWCA
Duluth, MN

Rochester, Minnesota

Susan G. Koman Breast Center Foundation
Dallas, Texas

Celeste Whitewolf, JD, BS
Native People's Circle of Hope
Tigard, Oregon

Lance Armstrong Foundation
Austin, Texas

Fond du Lac Reservation Business Committee

1720 Big Lake Rd.
Cloquet, MN 55720
Phone (218) 879-4593
Fax (218) 879-4146



Chairwoman
Karen R. Diver

Secretary/Treasurer
Ferdinand Martineau, Jr.

Dist. I Councilman
Eugene Reynolds

Dist. II Councilperson
Sandra M. Shabiash

Dist. III Councilman
Roger "Bouda" Smith, Sr.

RESOLUTION # 1061708

"Approving the Fond du Lac Band of Lake Superior Wiidookaage Cancer Plan 2007-2012"

The Fond du Lac Reservation Business Committee, on behalf of the Fond du Lac Band of Lake Superior Chippewa, hereby enacts the following Resolution:

WHEREAS, the Fond du Lac Reservation is a sovereignty, created by the Treaty of September 30, 1854, 10 Stat. 1109, as the perpetual home of the Fond du Lac Band of Lake Superior Chippewa, which possesses the inherent jurisdiction and authority to exercise regulatory control within the boundaries of the Fond du Lac Reservation; and

WHEREAS, it is the sovereign obligation of the Fond du Lac Reservation Business Committee, as the Governing Body of the Fond du Lac Band, under the Reorganization Act, 25 U.S.C. section 461 et seq., and in accordance with the Indian Self-Determination Act, 25 U.S.C. section 450 et seq., to assume the responsibilities of Self-Government; and

WHEREAS, the Fond du Lac Comprehensive Cancer Control Project has identified the critical need for cancer prevention, education, treatment, survivorship, care giving, and data collection services in the Fond du Lac service area; and

WHEREAS, the Fond du Lac Band of Lake Superior Wiidookaage Cancer Team has worked to develop a thorough and comprehensive cancer control and prevention plan; and

WHEREAS, the Fond du Lac Reservation Business Committee recognizes the efforts of the Wiidookaage Cancer team and the staff of the Human Services Division to address a critical disease affecting the Fond du Lac community,

NOW THEREFORE BE IT RESOLVED, that the Fond du Lac Reservation Business Committee fully endorses and supports the Fond du Lac Band of Lake Superior Chippewa Wiidookaage Cancer Plan 2007-2012; and

We do hereby certify that the foregoing Resolution was duly presented and acted upon by a vote of 4 for, 0 against, 0 silent with a quorum of 5 being present at a Special Meeting of the Fond du Lac Reservation Business Committee held on March 4, 2008, on the Fond du Lac Reservation.

Karen R. Diver
Karen R. Diver, Chairwoman

Ferdinand Martineau, Jr.
Ferdinand Martineau, Jr., Sec./Treas.

For more information contact:

Fond du Lac Human Services Division
Public Health Nursing Department
Fond du Lac Widookaage Cancer Program
927 Trettel Lane
Cloquet, MN 55720
Tel 218 879-1227

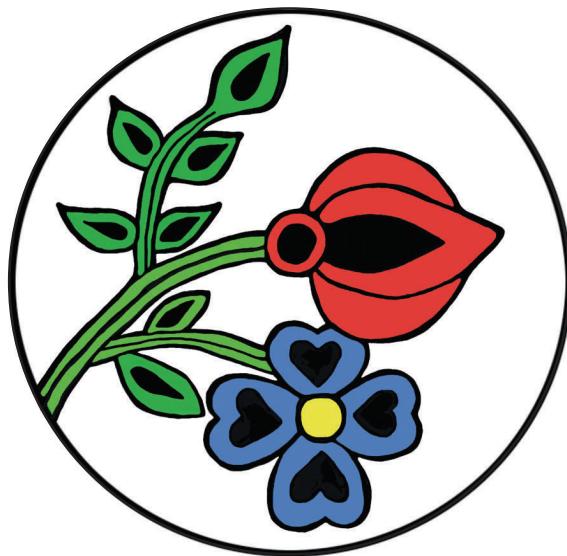
UNIVERSITY OF MINNESOTA

Cancer Center

We gratefully acknowledge and thank the University of Minnesota Cancer Center for funding the publication of this document.



Fond du Lac Band of Lake Superior Chippewa
1720 Big Lake Road
Cloquet, MN 55720



Fond du Lac Human Services Division
927 Trettel Lane
Cloquet, MN 55720

This publication was made possible through a grant from the Centers for Disease Control and Prevention:
Fond du Lac Reservation Cooperative Agreement Number U55/CCU522044-05: National Cancer Prevention
and Control Program.