

Health Indicators:

Awareness and Participation in Cancer Programs

Tahoe Forest Cancer Program



Committed to providing the highest quality cancer care

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May 28, 2008



Completed in partial fulfillment of graduation requirements for
the
2008 North Lake Tahoe-Truckee Leadership Program.

ABSTRACT

The Health Indicators pertaining to Awareness and Participation in Cancer Programs is a study to determine what the special needs are of cancer patients and families in the surrounding community. With ancillary programs already in place, how can the community become informed, and if interested, how can they participate.

The need is real enough, with the Cancer Center's population more than doubling in two years. Of those patients, how many would have need of special programs that the American Cancer Society provides.

We move forward from here to present, in the following study, our thoughts, questions, arguments, and results.

CONTENTS AND INTRODUCTION

We began this project wanting to identify effective indicators of our community's health and wellbeing, and therefore determine ways to improve it. While we recognized that the populations of North Lake Tahoe and Truckee are relatively healthy and active, there still exist significant barriers to care. For example, there is limited availability of basic services, prohibitive cost of the services available, geographic separation from county seats and major population centers, cultural disparities, extreme weather factors, and transportation difficulties that can make travel between even our own local communities problematic. Not to mention, many members of our communities believe that they are already living healthy lifestyles, therefore exempting them from participating in regular preventive care or screenings.

Our discussions wandered from classic measures of public health, such as immunization rates or hospitalization rates for preventable chronic disease, to the availability of safety net services, such as low-cost dental care or emergency crisis intervention. We discussed the availability of longitudinal data to look at health and wellbeing over time. But ultimately, we felt that many of these indicators were already being tracked, either by county health departments, or the hospital district. We needed to find an indicator that would have an impact on the provision of services, and therefore community wellness.

Through personal experience and anecdotal evidence, we soon realized that valuable services did indeed exist in our communities, but they were not being fully utilized for one reason or another. Why was this? Are the services not useful? Are they valuable, but not accessible? Or does the community not know about them?

A case in point involves the many services available through the new Cancer Center at Tahoe Forest Hospital and the American Cancer Society. Once a patient has been diagnosed, various services are available including; free transportation to medical appointments; support groups and counseling for patients and family; and beauty and self-image programs for patients during treatment. Each of these programs has the ability to dramatically improve the quality of life for local cancer patients, and have been qualified on a national basis, however they are drastically

under-utilized locally. This poses the question, how can we make best use of these existing resources to improve the wellbeing of our community?

The purpose of this project is to identify indicators that the Tahoe Forest Cancer Center and the local American Cancer Society (ACS) can use as a template for the future planning of their programs in the community. In the following sections of this report, we provide a brief background on the Cancer Center and its programs, as well as information on the American Cancer Society. We continue discussion by explaining our indicators in detail, their goal and purpose, and how this will be useful to local cancer programs. We will also discuss the limitations of the research presented and the methods used for gathering and analyzing the data. Finally, we present our findings and give recommendations on moving forward with this information.

BACKGROUND

The Tahoe Forest Cancer Center in Truckee opened in April of 2006 and in the first year there were 180 patients. In year two the center doubled their patients to 360, with approximately 22 percent of the patients living in Truckee. The remaining patients travel from the Lake Tahoe, Reno, and Carson Valley areas¹. The Center has a multidisciplinary team including medical doctors, nurses, pharmacists, laboratory technologists, nutritionists, social workers, financial services and other support personnel. They offer services for the early detection, diagnosis, treatment of cancer and follow up programs.

The American Cancer Society (ACS) is a nationwide, community-based voluntary health organization dedicated to eliminating cancer as a major health problem. They are committed to preventing cancer, saving lives, and diminishing suffering from cancer through research, education, advocacy, and service. Although the local office for the ACS is in Marysville, California, services in a satellite capacity have been available locally for several years.

The new Cancer Center was a tremendous advancement for our communities. Prior to the creation of this treatment center, patients and families had to travel either to Reno, Carson City, Sacramento, Davis, or even further for ongoing care. This was a tremendous burden on patients already experiencing great hardship. The new center allowed patients to focus on continuing their daily routines and maintaining their lives with minimal disruption. It also became a new locus for ACS programs.

Now that the Cancer Center is established in the community with a significant patient base, the ancillary services are poised to make a difference in the lives of those diagnosed with cancer. Based on discussions with Eileen Knudson, Director of the Tahoe Forest Cancer Center, and Karen Aaron Oncology Staff Nurse of the Cancer Center, we decided to target our indicators for three key programs:

- *Road to Recovery* is an American Cancer Society service program that provides round-trip transportation for cancer patients to their appointments. Transportation is provided according to the needs and available resources in the community. This is

¹ It is also interesting to note that a significant number of patients were coming from Northern Nevada. For those with California-based insurance, Tahoe Forest Cancer Center became the closest available treatment.

designed to be a volunteer-run program, fully funded and supported by the local American Cancer Society. This program is not currently operational locally, and does not have any active volunteers — yet.

- *Support Group Meetings* are currently available through the Tahoe Forest Cancer Center for cancer patients, their families and friends to help them adjust to life with a cancer diagnosis. Trained counselors help patients and their families cope throughout the course of treatment and beyond.
- *Look Good...Feel Better* is an American Cancer Society community-based, free, national service that teaches female cancer patients beauty techniques to help restore their appearance and self-image during chemotherapy and radiation treatments. Many major cosmetics' manufacturers donate products for this program that is fairly well recognized nationwide, and already entrenched in this community. Local businesses such as Mane Attraction in Truckee also participate.

All three programs have been proven to dramatically improve the quality of life for cancer patients, but are drastically under-utilized locally. Are people aware of these services? If they are aware of them, do they consider them useful?

Several other programs were also discussed, some of which are already in planning phase through other sources. Those addressed in this report are the ones identified as most urgent and beneficial. Ideas for other potential programs that have been gathered in this process will be shared with both the Tahoe Forest Cancer Center and the American Cancer Society.

DESCRIPTION OF PROPOSED INDICATORS

Our proposed indicators consist of a simple survey of the community's awareness and interest in the Cancer Center and ACS programs. Measuring the community's awareness and interest in these programs will determine if an outreach and education program is necessary, what that outreach might look like, and suggestions for other steps that might be employed to improve the programming.

We created this simple survey and distributed it throughout the community utilizing existing avenues, such as local Chamber of Commerce mailing lists, Business Expos, and community fundraising dinners. We considered sending the survey to past and present patients of the Cancer Center, but decided that there were too many concerns for patient privacy.

The survey questions were as follows:

1. Have you or someone you know been treated for cancer? Y/N
2. Have you or someone you know been treated for cancer at the Tahoe Forest Cancer Center?.....Y/N
3. Did this patient need someone to drive them to their physicians' appointments and/or cancer treatments? Y/N

4. Are you aware that there is a program provided by the American Cancer Society called the **Road to Recovery** that pays for transportation to and from these appointments, either with cab and bus vouchers, or reimbursement to those who drive? Y/N
5. Would the cancer patient that you know be interested in utilizing such a program? Y/N
6. How important would you consider this program? On a scale of 1-10, 10 being very important please list your number _____
7. Would you or someone you know be interested in volunteering and being trained as a driver to provide these services? If you answered yes please email your contact information to info@truckee.com..... Y/N
8. Are you aware that **Support Group Meetings** are offered at the Center for cancer patients, their family and friends on the first and third Monday of each month?..... Y/N
9. Do you know of someone touched by cancer that would be interested in these support programs? Y/N
10. Are you aware of the **Look Good, Feel Better** program co-sponsored by the American Cancer Society designed to help women overcome the appearance related side effects of cancer treatment? Y/N
11. Do you know of someone that would be interested in participating in the **Look Good, Feel Better** program? Y/N
12. Would the cancer patient you know be interesting and an Exercise for Energy class if it were available?
13. What other needs would you like to see addressed regarding the cancer center and its patients? _____

Questions 1 and 2 relate to the respondents personal experience with cancer. Questions 3, 7, and 9 directly gauge the awareness of our target programs, while questions 4, 8, and 10 are concerned with the value of these programs. Question 7 inquires about the interest in volunteering and training for the Road to Recovery program, and enables us to receive, discretely, critical contact information. Since the ACS is looking for volunteers for the Road to Recovery Program, we asked a specific question to gather this information. Finally, question 13 is seeking input from the community on the needs remaining.

PROMOTION AND UTILITY

Our indicators can be an essential component of the development of future local cancer programming. This survey was designed to demonstrate the varied public awareness and potential demand for such services. Results will be useful to the Cancer Center staff and ACS volunteers to determine how to allocate time and resources. If there is limited awareness of programming, outreach may be the answer. However, if there is no apparent demand for such

programming, other actions may be appropriate. Without appropriate data, the Cancer Center and ACS will lack direction, and may either miss an ideal opportunity, or misallocate resources.

The advantage of using these indicators is that it is a very simple gauge of awareness among the general public. It is a quick, easy, and largely accessible instrument to measure a rather straightforward topic. The most useful information to Cancer Center staff and the ACS are topline results.

The disadvantage is that the general public may not be the most appropriate audience. A cancer diagnosis can be a life-altering experience that can dramatically change a person's interactions and expectations. The general public can only pretend to understand this experience and the needs one may have. This instrument is also limited in its scope. We do not use this survey to probe deeper into the respondents' experiences or rationale, therefore, we cannot fully comprehend the answers we receive.

Finally, in developing and distributing these surveys, we recognized that this was an awareness tool in and of itself, and we fully intended to capitalize on this. While not a validated, scientific survey instrument, it met the goals of our indicator project, as well as the needs of the Cancer Center and ACS.

DECISION-MAKING BODY

Our process began by brainstorming many ideas within our group. Because there are members of our group who have been directly involved with the Tahoe Forest Cancer Center, we started with some understanding of how the eventual indicator may be used. Which direction we decide upon would dictate which body or bodies would be utilizing the information developed by and contained within the indicator. We ended up with a very specific indicator related to a specific element of patient care. Because of the focus of the proposed indicator, three affected bodies may utilize the indicator.

The first of these bodies that will utilize the information compiled via this indicator is the Tahoe Forest Hospital District. Although this will be from much broader perspective, because the Cancer Center is a part of the Tahoe Forest Hospital District, the hospital may utilize the information in the development of its own cancer-related programs in the future.

Our group worked directly with the Tahoe Forest Cancer Center and its staff to help identify an area related to patient care that we could help address. We met with the staff at the Cancer Center, to begin to discuss ideas regarding areas of need in the treatment process. In addition to the indicator that was developed, other ideas were discussed about potential improvements to patient care. The staff at the Tahoe Forest Cancer Center will be utilizing this information that has been developed via the indicator, in addition to the other suggestions that have been made.

Depending on how the improvements are carried forward, we see a direct role for the American Cancer Society to play in this process. The American Cancer Society already has a program called "Road to Recovery" that offers rides to various appointments for patients who need them. This program has not been developed and/or implemented in the Truckee/North Tahoe area, and the information developed throughout our process will be instrumental in getting this program up

and running in the local area. In our process of finding the area of greatest need in this treatment process, we were also able to gather contact information for volunteers who are willing to help with this program. The data gathered in the development of our indicator identified this as the greatest area of need for some patients. The American Cancer Society's local Truckee chapter can take the information that we have developed and

GOAL AND PURPOSE

Our team initially came together under the general topic of "Healthcare." Several of us within the group have had personal experiences that resulted in our wanting to provide additional improvements in local health care services. As mentioned in the summary, three of our team members have had very recent direct experience with cancer treatment; one survivor (diagnosed less than 18 months ago); the mother of a young survivor (diagnosed a little over two years ago); and the relative of a current cancer patient with a poor prognosis. Given this direct experience and the need to narrow our field down to a level that would allow us to develop an indicator that would be immediately useful, we worked our way to the specific medical field of oncology.

As stated above, in the development of this indicator, we have not only identified the need, but we have also begun to define the solution. By working with the staff at the Tahoe Forest Cancer Center and the American Cancer Society we already have the understanding of how we can take the identified "problem" and immediately begin to implement a solution. It may be used to influence policy, but will more importantly almost-immediately lead to improvements in patient care in the Truckee-North Tahoe area.

METHODOLOGY

Once we identified our area of greatest interest, we were then able to specify the affected groups, or the "stakeholders." Because our indicator was going to be in the area of local oncology services, two of the main stakeholders are the Tahoe Forest Cancer Center and the local chapter of the American Cancer Society. We saw the Cancer Center as the main source of information for our "data" and the American Cancer Society as the venue needed to eventually implement the proposed improvement, solving the identified need and filling an identified gap in local cancer patients' care.

After meeting with the staff at the Tahoe Forest Cancer Center, and having a tentative idea of where the greatest needs lie, we set out to gather information from both cancer patients and those affected by cancer treatments to confirm (or refute) our preliminary findings. Additionally, there is a member of our team who is involved with the local chapter of the American Cancer Society who was able to provide us with some direction.

The group developed a survey that was to be sent out to a database from the Truckee Donner Chamber of Commerce. The survey (a copy of which is included in the appendices and is summarized in the "Description of Proposed Indicators" section) sought input from the general public as well as those affected by cancer. It began by asking if the respondent or someone they knew had been treated for cancer and if so, were they treated locally. It then led to a series of

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questions asking about certain needs and the whether the referenced patient would utilize certain support programs that are either currently offered or may be proposed in the future.

The surveys were initially made available at the Truckee Donner Chamber Business Expo. The responses on these first few surveys gave us some good feedback on ways that the survey itself should be improved to provide us with more useful results (e.g., the ability to provide contact information if they were interested in volunteering for the proposed program). Changes were subsequently made to the final version of the survey, which was developed in “Zoomerang”.

A link for the survey was sent out via e-mail to the Truckee Donner Chamber of Commerce’s mailing list. It was the results from these particular surveys that were used to determine the legitimacy of our originally proposed idea. Approximately (76) responses have been received.

Ultimately, the survey fulfilled two purposes: to help identify whether there were any perceived areas of need in local cancer treatment; and to find out what interest exists in utilizing the proposed programs designed to help the patient.

Although the group went into the survey process with an idea for the proposed indicator, the survey results helped solidify that theory. From our discussions with the Cancer Center staff, providing rides for patients was identified as a need, but other ideas for support programs were proposed as well. The survey helped reinforce the fact that unmet patient needs do exist, and it also confirmed that the Road to Recovery program is one program that would meet one of these needs and would be the most utilized of the programs mentioned in the survey.

The results highlight some very interesting and eye-opening facts about cancer itself, as well as cancer treatment in the Tahoe-Truckee area. As shown in Figure 1, approximately 60 percent of the respondents said either they or someone they know has been treated for Cancer. Additionally, approximately 50 percent of them know someone who has been treated for cancer at the Tahoe Forest Cancer Center.



FIGURE 1 – THE ABOVE QUESTIONS WERE ASKED TO RESPONDENTS IN ORDER TO GAIN THEIR CONNECTION TO THE SUBJECT.

Of those who either have been through treatment or know someone who has, 65 percent said this patient needed someone to drive them to physician appointments and cancer treatments.

Figure 2 compares awareness of the programs listed with the number of people who said they would utilize such a program if it were made available to them. (Note: for the Exercise for Energy program, no awareness is shown because it is not a program that is in place).

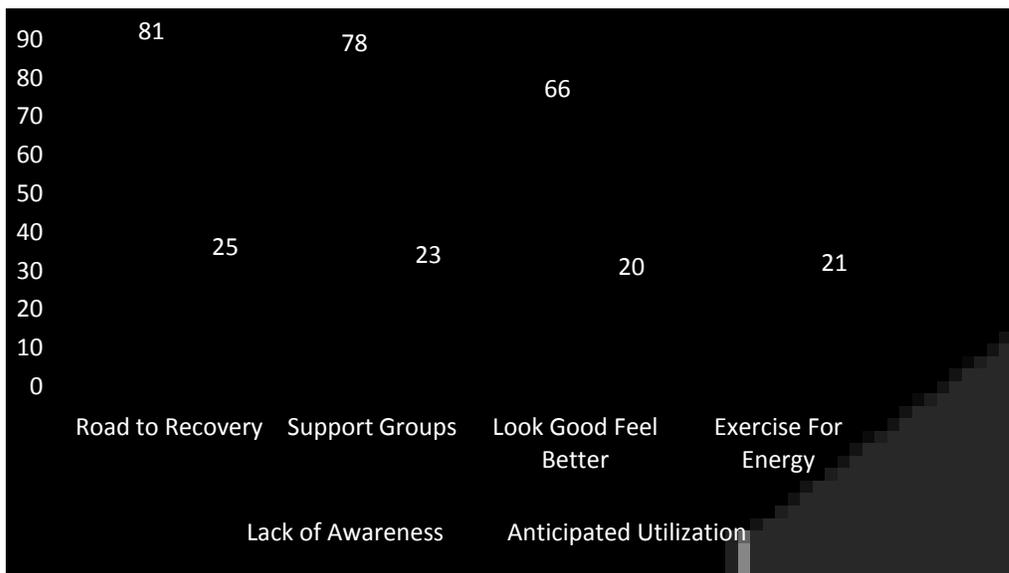


FIGURE 2 – THE ABOVE SHOWS THE LACK OF AWARENESS OF CANCER PROGRAMS VS. HOW MANY PEOPLE WOULD UTILIZE THE PROGRAMS. [NOTE: “EXERCISE FOR ENERGY” IS A NEW PROGRAM, THEREFORE AWARENESS WAS NOT INCLUDED].

Some highlights of the survey results (which have been summarized in Figure 2) include:

- 25 percent said they would be interested in utilizing a program which offered rides to patients who need them
- 23 percent said they would be interested in participating in support groups
- 20 percent said they would be interested in participating in the Look Good, Feel Better programs
- 21 percent said they would be interested in an Exercise for Energy class in Truckee

The results demonstrated that the proposed service to offer rides to cancer patients was in greater need and is more likely to be utilized than the other programs referenced.

One question on the survey asked the respondents to identify how important (on a scale of one to 10) they consider the proposed program to offer rides to patients. As shown in the results to this question summarized in Figure 3 below, the greatest number of respondents (37 percent) identified this as a 10. This not only demonstrated that the need for rides is one of the greatest needs, it also has the potential to be the most utilized. For the 73 responses to this particular question, the median level of importance assigned to this proposal was 8.3 out of 10.



FIGURE 3 – RESPONDENTS NOTED THE LEVEL OF IMPORTANCE IN REGARDS TO THE AMERICAN CANCER SOCIETY’S ROAD TO RECOVERY PROGRAM. [NOTE: 37% IDENTIFIED THIS PROGRAM AS A 10, “MOST IMPORTANT”].

LIMITATIONS

The methodology for collecting our data resulted in good information. But as with any survey, the more responses the better. The time frame we had to work under did not allow us to seek as many responses as we would have preferred.

Although some surveys were made available at the Truckee Donner Chamber of Commerce's Business Expo, the majority of the survey responses were received via the electronic survey which was only available online. The link was sent to the mailing list of the Truckee Donner Chamber of Commerce members. This limited our respondents to those with regular access to computers and e-mail, who are most likely those with moderate to high incomes. The results may have been different if the survey targeted lower income respondents. Additionally, the respondents would have been the chamber members themselves and not necessarily employees of those businesses.

Again because of the mailing lists that were used, the recipients of the request represent more of a general public view than one that would have been targeted to cancer patients (Note: due to privacy issues we were not able to contact patients at the Tahoe Forest Cancer Center directly).

Due to a misunderstanding from a Chamber employee, a draft survey was initially mailed out, rather than the version that had received the final edits. This version of the e-mail and the survey itself contained a number of errors, which may have affected those who chose to respond to the survey.

Although certain limitations existed throughout our process, our team believes that the results of the survey contain very helpful information and are sufficiently valid to move forward with our recommendations.

RECOMMENDATIONS

Findings of the survey indicated that a large number of people are affected by cancer. The fact that patients can now be treated locally is significant. However, the fact remains that there are still those with needs to be fulfilled, as in the elimination of barriers for a number of people needing assistance in transportation to and from treatment.

Present the findings of the survey and report with the Tahoe Forest Cancer Center and American Cancer Society (ACS).

Suggest Tahoe Forest Cancer Center design a modified survey for their patients as an aide to determine awareness and need of their programs. This survey could be done internally and distributed at Truckee's Relay For Life on July 19-20, 2008 for additional information for the Center.

Per our findings, the program that was found to be the most needed, The Road to Recovery through the American Cancer Society volunteer network is on the road to implementation. The names of the survey takers that indicated an interest in volunteering to be drivers for the Road to Recovery will be provided to the ACS.

Additional awareness and volunteer driver solicitations will be performed at the 24 Hour Relay. For many cancer patients, a lack of transportation presents a serious roadblock to recovery. Encourage volunteer efforts for rides to life saving treatments. Provide the ACS 1-800-227-2345 for potential volunteers to call.

SUMMARY

The experience of gathering the information for our health indicators report has been extremely rewarding. This is a living project that we have enjoyed seeing grow, thrive and have already witnessed some positive returns.

What began as a nebulous project that was to involve some aspect of health in our community has been transformed into a project that involves community awareness and interest in the Cancer Center and American Cancer Society programs. This was through no accident, as our committee includes: a breast cancer survivor, a mother of a young cancer survivor, a relative of a current cancer patient with a poor prognosis, and, certainly, everyone on our committee knows of someone touched by this disease.

The North Lake Tahoe region is home to many who pride themselves on their health and care of their body, mind and spirit. It is perhaps because of this that those who believe they are in better health than the norm are the last to realize that something is not right — health wise. It may be because of this that the cancer treated in our region is sometimes a later diagnosis.

After determining our course of action to assemble the committee's information, many positive elements occurred that provided, in some cases, immediate gratification and encouragement. While a pronounced number of those interviewed did not know about the American Cancer Society's Road to Recovery program, it was extremely rewarding to note that we, conversely, learn of the number of respondents who would be interested in training to become drivers for the program. One such person is a retired nurse who clearly understands the challenges and burdens cancer patients have, among these are traveling to potentially life-saving treatments. She has volunteered to start the program in Truckee.

Another positive example is a communication from Terry Gardiepy, the Community Services Manager of the American Cancer Society, Marysville Field Office. Teri volunteered a member of her department to address civic groups about the need for drivers with the Road to Recovery program.

What began as an exercise on paper evolved into a hands-on experience of educating the community about cancer services available to patients and families. From that clinical realm came a program that has *already been set in motion*. Volunteers and organizations have already come forward to support the program that will help to create a legacy now and into the future for our community.

APPENDICES

Example of survey sent:

North Lake Tahoe-Truckee Leadership Class - Oncology Survey

Greetings! We are students of the North Lake Tahoe-Truckee Leadership program and are working to make positive changes. We would appreciate it if you could take a few moments to fill out the attached survey regarding services available through the Tahoe Forest Cancer Center and/or the American Cancer Society.

Your answers will be anonymous and help make a positive step forward with an important program in our community. Please take the time to answer these questions, as you are making a personal contribution in this program that can create a legacy for our cancer patients.

Please respond by 5:00 pm, Monday, May 12th.

Thank You!

Bridget Cornell

Ruth Geresy

Pattie Lesser

Trina Orr

Michelle Prestowitz

2008 North Lake Tahoe-Truckee Leadership Group

North Lake Tahoe-Truckee Leadership Class - Oncology Survey

The Tahoe Forest Cancer Center opened in April of 2006 and in the first year 180 new patients were treated. In year two the center doubled their patient census with approximately 88% of the patients living in Truckee and the surrounding communities.

1 Have you or someone you know been treated for cancer?

YES NO

2 Have you or someone you know been treated for cancer at the Tahoe Forest Cancer Center?

YES NO

3 Did this patient need someone to drive them to their physician appointments and cancer treatments?

YES NO

4 Are you aware that there is a program provided by the American Cancer Society called the Road to Recovery that pays for transportation to and from these appointments, either with cab and bus vouchers, or reimbursement to those who drive?

YES NO

5 Would the cancer patient that you know be interested in utilizing such a program?

YES NO

6 How important would you consider this program? On a scale of 0-10, 10 being very important please select your number.

1 2 3 4 5 6 7 8 9 10

7 Would you or someone you know be interested in volunteering and being trained as a driver to provide these services?

If you answered yes, please email your contact information to
info@truckee.com

8 Are you aware that Cancer Support Group meetings are offered for patients, their family and friends on the first and third Monday of each month?

9 Do you know of someone touched by cancer that would be interested in participating in these support programs?

10 Are you aware of the Look Good, Feel Better program co-sponsored by the American Cancer Society designed to help women overcome the appearance related side effects of cancer treatment?

11 Do you know of someone that would be interested in participating in the Look Good, Feel Better program?

12 Would the cancer patient you know be interested in an Exercise for Energy class in Truckee?

13 What other needs would you like to see addressed regarding the Tahoe Forest Cancer Center and its patients?

References:

Inverviewees:

1. Eileen Knudson, Executive Director Tahoe Forest Cancer Center
2. Karon Aaron, Oncology Nurse, Tahoe Forest Cancer Center
3. Terry Gardiepy, the Community Services Manager of the American Cancer Society, Marysville Field Office
4. Libertine (Libby) DelRosario, Patient Services Staff Assistant, Sacramento Field Office

Other Resources:

1. American Cancer Society Website
2. Road to Recovery Website
3. Tahoe Forest Hospital Website
4. Tahoe Forest Cancer Center collateral
5. American Cancer Society collateral
6. Relay for Life collateral