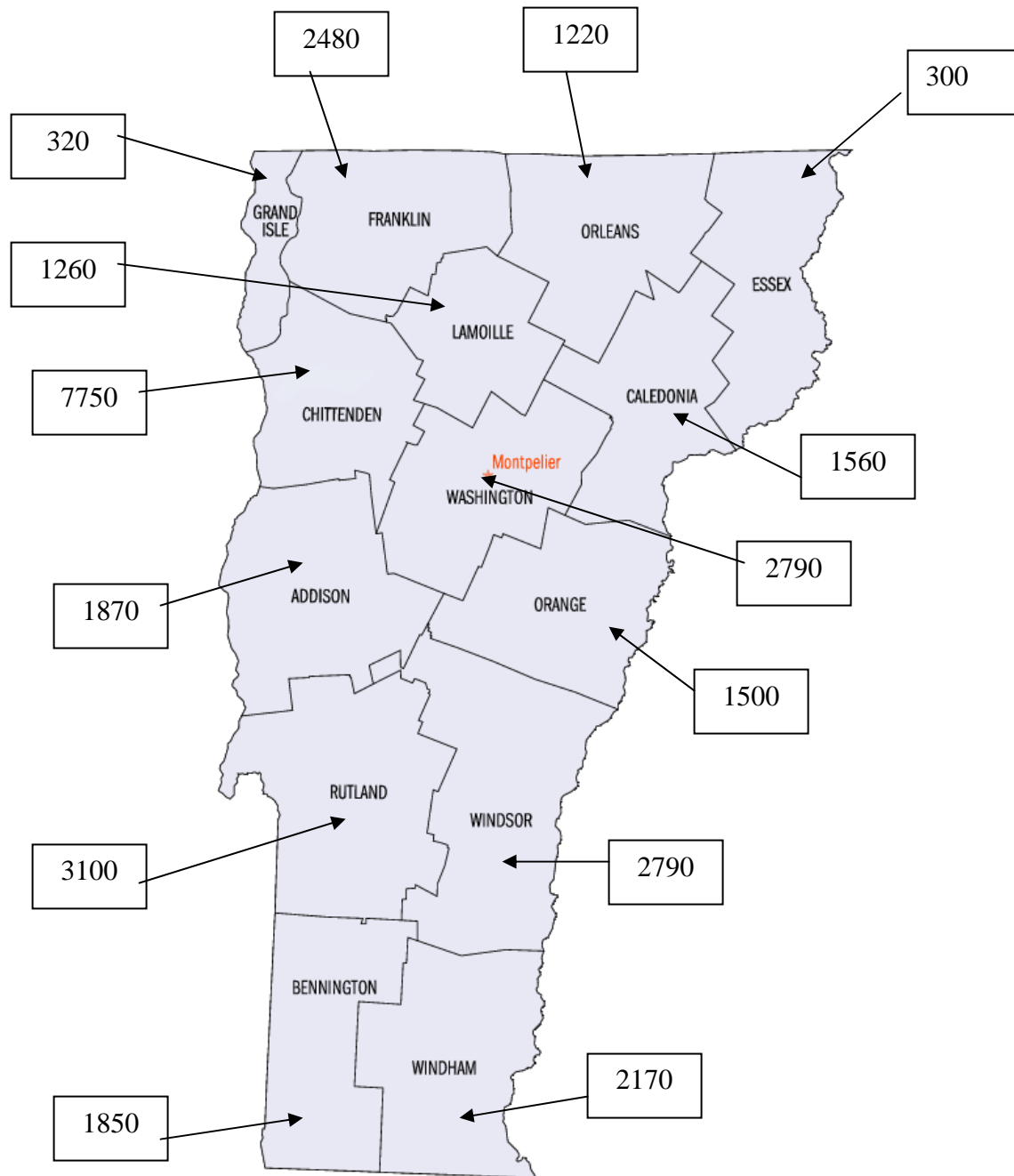


## ***Cancer Survivorship in Vermont:***



***What we are learning and what we want to know.***  
Vermont Cancer Survivor Community Study

***Cancer Survivorship in Vermont:  
What we are learning and what we want to know***

Some history.

In 2005, the Vermont State Cancer Plan was issued by the Vermont Department of Health. One of the goals of the Plan was to “Improve the quality of life for people living with, through and beyond cancer.” At the time it was estimated that over 28,000 Vermonters were living with a diagnosis of cancer. The Plan states that “emotional support, on-going health maintenance, and social connections can greatly improve the quality of life for cancer survivors.” An ad hoc committee of cancer survivors was created to work on this goal. In 2006, this committee was formally organized as the Vermont Cancer Survivor Network (VCSN).

Surveying survivors.

In the spring of 2006, the Plan funded a focus group survey of cancer survivors. The major challenge for the survey was recruiting participants. Issues such as patient confidentiality and the feelings that people diagnosed with cancer were facing made it difficult, if not impossible, to reach out to survivors. The contractor worked with existing cancer support groups to hold surveys in 5 parts of the state. The results of the surveys were:

**Need for Support**

The most predominant theme throughout the various threads of the focus group study was that support plays a critical role for cancer survivors. Despite its importance, the need for peer support is being poorly met in the state.

**Need for Information**

The majority of focus group participants described a profound and ongoing desire for information. Survivors want to have information offered to them rather than always having to search for it.

**Transitions and Emotional Well-Being**

The end of treatment was experienced as a difficult and sometimes frightening transition, even when outcomes are positive. Survivors are generally surprised by the depression and anxiety that occurs during these transitions because they are rarely advised that a period of emotional adjustment is common. Emotional support and counseling, like information, needs to be offered on an ongoing basis as individuals' needs change.

**Medical Care**

Survivors were generally satisfied with the quality of their cancer-related care. The challenge for many comes in the area of routine care and after-care. Lack of clarity about whether to be followed by an oncologist or primary care provider is a concern.

**Financial Concerns**

While almost all participants had health insurance of some kind, cost and underinsurance in its various forms were major issues for many. The link between insurance and employment is problematic.

## **Decision-Making and Navigating Systems**

Participants wished in hindsight that they had known how to be more involved in making decisions. The need for assistance with service coordination, advocacy, and navigating service delivery systems was a theme across the focus groups, but few had received this type of assistance.

### The grant.

With the focus group results in hand, the two founders of VCSN, Ellen Fein and David Cranmer, approached Dr. Berta Geller, a researcher at the University of Vermont, to see if there was a better way to determine the unmet needs of cancer survivors in Vermont. Geller, having experience in the development of a mammography registry, submitted a grant proposal to the National Cancer Institute to test if a registry of cancer survivors could be created in Vermont.

The original application did not receive funding, but based on the feedback received; the proposal was revised and submitted in 2007, narrowing the focus of the study to the four northwestern counties of Vermont.

The *Vermont Cancer Survivor Surveillance System* received R-21 funding from the National Cancer Institute (4/08-4/10). The goal was to test if we could start a population based registry of cancer survivors, using community based participatory research. Geller started working with the cancer registrars in the four local hospitals to develop a confidentiality agreement and enlist the support of each hospital.

There were two aims to be addressed by the study. One, determine if cancer survivors would be willing to participate in a registry. Two, demonstrate how the information from this registry would be used.

## **Aim 1- Will Cancer Survivors Participate in Registry**

### Study initiation.

As the funding was for community based research, UVM reached out to the VCSN to recruit a steering committee to oversee the implementation of the grant. The committee consisted of cancer survivors from each of the four counties, cancer registrars, and survivor advocates, along with the UVM research team.

A name was chosen for the project, the *Cancer Survivor Community Survey* (CSCS), and printed information material was created. An initial letter requesting participation was developed along with a one-page survey. This package would be mailed out to patients from each participating hospital's cancer registry with a cover letter from the hospital's Chief Executive Officer. In the two American College of Surgeons (ACOS) Commission on Cancer (COC) registries we invited patients diagnosed with cancer from 1990 through 2006, and in the two non-ACOS COC registries we invited patients who were diagnosed in 2006.

### Building community awareness.

Since there were concerns about the public awareness of the local cancer registry, as well as the need to collect information, survivors from each county were recruited to join a local task force to spread the word. Articles and letters were printed in newspapers and in hospital newsletters. Volunteers appeared on local public access and broadcast television, and spoke at senior citizen centers and to local cancer support groups. Posters and flyers were distributed in local gathering places.

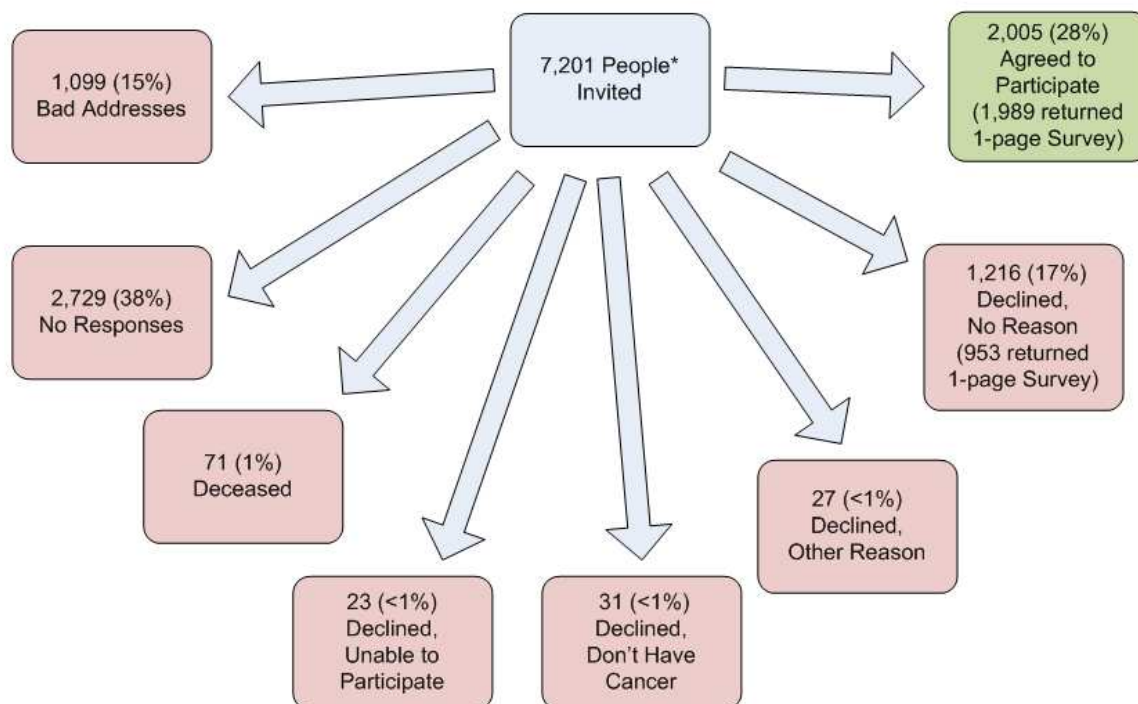
The invitations to participate in the registry were mailed on a county by county basis starting in November 2008. The first of two lessons learned was that many invitations came back undeliverable. The UVM research team was able to update many addresses and re-send the packages (and update the local cancer registry). The second was that many Vermonters travel to warmer climates in the winter, leading to many late returns in the spring.

#### Results from the initial mailing.

Over 7,200 invitations were mailed to survivors, in which they were asked to complete a short demographic survey, even if they chose not to participate in the registry. These data are being used to compare those who agree to participate with those who do not.

Of the total invited to participate, 1,099 were returned for bad addresses. A total of 3,302 responded, 2,005 agreed to participate in the study, 1,297 declined, of these a total of 2,942 filled out a short demographic survey.

#### CSCS Responses



Group 1: 5,196 (72%) – Not Participating

Group 2: 2,005 (28%) – Participating

\* These are eligible people. More people were invited initially, but selection criteria subsequently changed, and some people were dropped.

As of 1/20/2010

## Demographics

	Agreed to participate	Only completed the survey
Average age	67	71
% of males	40%	44%
Average age of males	68	72
Average age of females	62	70

### Are you...?

Married	70%	60%
Divorced	10	12
Widowed	12	21
Separated	1	1
Never married	6	5
A member of an unmarried couple	2	1

### Are you currently...?

Working for pay at a full time job	28%	12%
... at a part time job	14	8
Not working	39	29
- retired	48	40
- looking for work	2	1
- a home maker	5	3
- a non paid volunteer	4	2
- Unable to work due to a disability	6	4

What is your highest level of education that you completed?

	<b>Agreed to participate</b>	<b>Only completed survey</b>
Less than high school	7%	18%
High school graduate	24	33
Technical school or some college	21	20
College graduate or more	49	29

Which of the following best indicates your family's annual income in 2007 from all sources and before taxes?

Less than \$20,000	11%	23%
Between \$20,000 & \$35,000	16	24
Between \$35,000 & \$50,000	18	23
Between \$50,000 & \$75,000	20	15
\$75,000 or more	28	15

Areas of research about cancer survivorship important to you.

Physical health	67%
Emotional health	59
Activities of daily living	46
Relationships with doctors	45
Financial well being	36
One's ability to think	30
Spiritual health	27
Social health	22
Employment	18

### Quotes from study participants.

Over 200 responders wrote notes on the survey. Many used the back side of the survey or added several hand-written pages to their response. Here are some examples...

- Tried to apply for financial assistance at your facility and for cancer patients/survivors in my home county when we encountered a necessary household repair. Told didn't qualify because I wasn't an "active" cancer patient in both settings. Sorry folks, once you're dx'd w/cancer it's still there just because you're not barfing from chemo or radiation you are always a statistic and a person with cancer.
- I'm extremely grateful for the extraordinary compassion and care at the Breast Care Center, FAHC. The reach-out of the Reach for Recovery volunteer at the onset of my diagnosis was very encouraging and helpful. I'm a journal writer and writing in my journal was amazingly therapeutic and healing.
- I had no support of any kind not from my family or any one else. I was laughed at, and called names also told I was now a one headlight because I only had one breast. Now it is too late to offer me any help or support of any kind. I live alone now and that is the way I want it. I do not want to be around other people. Maybe I am a recluse but at least I am not being laughed at or being called names any more.
- If I find out I have breast cancer again I [surely] will not go and have anything done. I'd rather die than go thru this all over again. It isn't worth it to me.
- Huge treatment costs and 5 years medications even with insurance a real hardship.
- Proud Vermonter won't see doctor because he can't afford it.
- My attitude is different from that of many cancer survivors. I prefer to forget that I am one of them, and go on with my life as long as possible (which is not long). I hope you won't remind me of cancer anymore.
- Examine. Look for change. Early diagnosis=early cure or dormancy. I still have dormant prostate cancer. Either that or 84 years has ruined my sex life.
- I am vertical and ventilating. Enjoy a beautiful sunrise. I am fortunate.
- I don't like the word survivor. I realize it has many positive connotations, but it carries with it its opposite... in order to be a "survivor," you must first be a "victim." I don't have a better word yet. Maybe you can help us find one.

### Themes from initial survey comments.

People used the following resources:

- Complimentary health care providers
- Financial aid
- Web sites, books

- Social, emotional and spiritual support from family, friends, volunteers, health care providers, churches

Examples of suggestions for resources for cancer survivors

- Like cardiac rehab why not something like this for cancer survivors?
- Support for children and teens of cancer patients
- Information about what symptoms may signal recurrence
- Advice / advisor 1 yr post treatment to go over needs at this time

Some people who were invited did not have cancer.

- Our cancer registries are required to register cases that are suspicious for malignancy findings. When they turn out to be benign they may not be removed from the registry.
- What constitutes a reportable case has changed over time.

Many people called or wrote that they did not have cancer.

- Cancers that required nothing more than surgery were often not thought of as a cancer such as melanomas, carcinoids, come sarcomas, polycythemia vera.
- One woman did not know that an oncologist was a cancer specialist.

### Discussion

We tested the feasibility of starting a cancer survivor registry for the purpose of learning about the effects of having been diagnosed and treated for cancer and were successful in recruiting 2,005 survivors willing to be invited into future research studies. Despite the considerable community involvement to explain the purpose of the registry those who volunteered to be registered were more likely to be urban, more educated, have higher incomes and less likely to be working full time. It is disappointing to not have an equal representation of rural, low income, and less educated cancer survivors in the registry because we expected that the community-based participatory approach would increase participation.

Our study was different than other studies because it required little effort to participate. A survivor could participate in two ways: complete a one page survey (2,942/6,031; 49% participation) or agree to be in the registry and available to be invited into future studies (2,005/6,031; 33%). Because of the two easy ways to participate and the community involvement in getting the word out about the study we expected a high response and participation rate. The participation rate for joining the survivor registry was higher than or similar to other cancer survivor studies that used cancer registries to recruit participants. Some cancer survivors do not consider cancer important to them; others prefer not to be reminded of their cancer; while others think that their stories are uninteresting. We had hoped that our effort to get the word out about our study would enable us to increase our participation rate. Perhaps our task force volunteers were not sufficiently representative of all the sub populations that exist within the communities and therefore we were unsuccessful in reaching the lower Social Economic Status (SES) population.

Several major national reports have highlighted that the underserved, those with low incomes, low educational attainment, members of racial and ethnic minority groups and those living in rural areas, have poorer outcomes from cancer. However, the survivorship experience of the underserved is not well studied partially due to poor enrollment into studies. Lower SES may make it more difficult for survivors to participate due to cost of travel, care of others, longer and less flexible working hours and literacy issues. In our study in addition to lower income and less education we found that working full time was correlated with not participating. Also, underserved populations may have an inherent distrust for the health care system and science in general.



## Conclusion

We are pleased that for almost all the subgroups in our study we have a large number of participants willing to be invited into future research studies. We believe that we have sufficiently large samples of most subgroups to do future research among the cancer survivors, including 66 with less than a high school education, 160 whose annual income is less than \$20,000 and 823 who live in rural areas. We encourage others to use our registry to conduct future research. More research is needed to learn how to increase participation in survivorship research among the underserved populations.

## **Aim Two – Better Understanding of Cancer Survivors’ Needs**

For the second phase, the steering committee developed, tested and conducted a 12-page survey to gather information about survivors' needs and identify unmet needs. The purpose is to use the research to improve services and support for Vermont cancer survivors.

The research team is analyzing results of the needs survey, which was completed in 2010. The survey was sent to the 2,005 members of the survivor registry. Of those, 1,668 people, or 83 percent, responded.

Sample page from survey.

6. EMOTIONAL, SOCIAL, AND SPIRITUAL NEEDS. Please check only ONE of the three boxes to the right of each statement to indicate that you had no need in that area, if you had a need and it was met, or you had a need and it was not met.

SINCE YOUR CANCER DIAGNOSIS, DID YOU NEED...	No need or not applicable	Had need and it was met	Had need and it was not met
a. help in figuring out what was most important in your life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. guidance in coping with mixed advice from family and friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. someone to talk with when sadness overcame you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. opportunities to explore religion and/or spiritual practices?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. opportunities to share your religious and/or spiritual practices with others?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. opportunities to try mind/body/spirit therapies such as yoga, tai chi, or massage?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. more contact and support from family members?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. more contact and support from non-family members?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. a group or person with whom you felt safe expressing how you really feel?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. help sorting out your feelings about death?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. help finding ways to reduce your worrying?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. EMOTIONAL, SOCIAL, AND SPIRITUAL NEEDS – CONTINUED

SINCE YOUR CANCER DIAGNOSIS, DID YOU NEED...	No need or not applicable	Had need and it was met	Had need and it was not met
l. help learning how to cope with your sometimes catastrophic fears?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. help managing your concerns about the cancer coming back?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n. help knowing how to support your partner and/or family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o. help dealing with the impact that cancer has on your relationship with your partner?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p. to talk with others who have experienced cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q. help handling the topic of cancer in social and/or work situations?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r. help trying to make decisions about your life in the context of uncertainty?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
s. help reducing stress in your life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

OPTIONAL COMMENTS ON EMOTIONAL, SOCIAL, AND SPIRITUAL NEEDS:

While results are preliminary, the study found that survivors' needs and unmet needs were related to factors such as age, sex, type of cancer, number of treatments, education and other characteristics. For example, male survivors who were older (70 or above), who had been diagnosed with melanoma at Stage 0 to 2, and treated with one to two types of treatments, tended to have lower needs. On the other end of the spectrum, female survivors under age 60 who were diagnosed with lung or multiple cancers at Stage 3, and who had four or more treatments, tended to have higher needs.

When looking at where the unmet needs were, 30 percent of respondents said they had unmet needs in the area of emotional, social and spiritual support; 25 percent said access to information; 23 percent said help with physical issues; 18 percent said access to care and services; and 14 percent said assistance with economic and legal issues.

The top cancer survivor needs (whether they were met or unmet) were:

1. To feel like you were managing your health together with the medical team.
2. More information about after effects.
3. Information provided in a way you can understand.
4. Assurance your doctors talked to each other to coordinate your care.
5. More information about your cancer.

The top cancer survivor unmet needs were:

1. Help in reducing stress in your life.
2. More information about after effects.
3. Help finding ways to reduce your worrying.
4. Help managing your concerns about your cancer coming back.
5. Help dealing with the impact of cancer on your relationship with your partner.

A closer look found a need for greater coordination of care, and more information about side effects and after-effects of treatment, as well as better access to complementary and alternative medicine. There were also unmet needs in the areas of sexual function/fertility issues: adjusting to body changes and dealing with partner.

The results of this survey will be used in developing the survivorship goals for the Vermont State Cancer Plan as well as in planning for future VCSN activities.

As part of the survey, survivors were invited to write in optional comments on unmet needs. Many individuals voiced that they may have made a different decision if they had known about the long term effects of their treatment. There also seems to be a lack of long term support options for the period of time after treatment as well as for people who have less "common" types of cancer.

Here are some examples of the responses...

- "The medical profession was completely unsupportive of alternative treatment as they did not recognize any other treatment than surgical removal."
- "My care became splintered for me. Two of my physicians have left and I do not feel as connected or supported now."
- "You are told what has to be removed and why, but not how it will affect you."
- "Would have like information on natural herbal treatments. Nothing was offered."

- “I believe that it is important for patients/survivors to learn of the various ways (diet, exercise, meditation, etc.) that they can help themselves, not just during treatment, but after treatment is over.”
- “The Internet, while useful, can be a source of great anxiety: at least it was for me.”
- “The biggest problem was not being able to talk about my cancer and get support, you feel alone and helpless.”
- “I would like to see [medical professionals] have more communications. On several occasions I was left to clean up the mess where one doctor did not know what the other was doing. I was the one caught in the middle left holding the IV bag.”
- “There needs to be more for young survivors.”
- “Once I was done with treatment I was sent out to live my life on my own. No further information or resources was given to me.”
- “Sometimes it is very difficult for my family to understand how I feel and worry about my cancer coming back. It adds a burden on them.”
- “What I really needed was a group/support system after radiation to get back to living life.”
- “Surviving financially kept me up almost as many nights as the chemo. I will never fully catch up and retirement is out of the picture...and I am one of the success stories.”
- “Cancer patients are going without treatment or have inadequate treatment because of lack of funds and health care. This is a disgrace that must be addressed.”
- “It seems that the cure for one problem leads to a chain of other problems.”

### **Additional activities.**

Since receiving the NCI grant, a secondary grant from a local foundation was received to develop and evaluate a peer social support system in the three most rural counties. To do this, the University of Vermont contracted with the VCSN to expand a program they had developed called “Kindred Connections”. This is a volunteer program that trains cancer survivors to provide peer support for other survivors in their community. It was piloted in 2007-08 in two of the counties, and was able to expand into the third. The volunteers are supported through follow-up training sessions. To date, over 140 volunteers have been trained in these three counties.

There are plans to apply for additional funding to make this a state-wide cancer registry.



For the Cancer Survivor Community Study

David Cranmer, *Vermonters Taking Action Against Cancer*, [www.vtaac.org](http://www.vtaac.org)

<sup>1</sup> Are Cancer Survivors Willing to Participate in Research?

Geller BM, Mace J, Vacek P, Johnson A, Lamer C, Cranmer D.  
J Community Health. 2011 Feb 11. PMID: 21311959