

DEFEAT Cancer Annual Report to the Lance Armstrong Foundation



Community Program Subject Area: Exercise & Nutrition Narrative Report: Interim

Name of Organization: St. Charles Foundation
Mailing Address: 2500 NE Neff Rd, Bend OR 97701
Web Address: www.defeatcancer.info
Contact Person's Name: Archie Bleyer, MD
Title: Director
Phone: 541-383-6998
Fax: 541-385-6341
Email: ableyer@cascadehealthcare.org
Total Amount of Grant: \$149,589.89
Year One Amount: \$42,031.63
Project Name: **DEFEAT Cancer**
Grant Type: Community Program
Subject Area: **Exercise & Nutrition (E&N)**
Projected number of individual participants: 120 survivors and 60 spouses (Year 1)
Interim Report Due Date: March 1, 2008

Instructions for Form: This is a one-year interim reporting form for multi-year grantees. Please thoroughly answer all applicable questions. Subsequent funding will be released only after the completed interim report, work plan and budget have been approved by LAF.

1.) Brief Description of Project:

DEFEAT Cancer: **Diet** **Exercise** **Famiy** **Education** **Attitude** **Thriving**

Focus: **E**xercise and **N**utrition (**E&N**ergy) to improve survivorship after cancer

Focus: **S**oaring **S**pirits annual retreat and refresher course

www.defeatcancer.info

2.) Describe the specific goals and/or objectives of the project, as outlined in your original grant application to the LAF:

1. To teach cancer survivors how to include physical activity in their weekly year-round routine (within 3 months for each new registrant) (years 1-3)
2. To educate cancer survivors how to improve their nutrition and daily eating habits (years 1-3)
3. To demonstrate that both above life-style objectives can be sustained (years 2-3)
4. To prevent and/or reduce depression, fatigue and loss of confidence after therapy (years 1-3)
5. To document individual and collective progress of survivors and spouses and to expand participation geographically and ethnically (years 1-3)
6. To reach rural patients and those disconnected from health care services by geographical and social barriers (years 2-3)

3.) Describe the activities completed to date in order to achieve the specific goals and objectives listed above.

Goal 1: **Physical Activity**

Year-Round Program

Daily: Each participant was provided with a pedometer and expected to record their daily number of steps and other physical activity on one of two **DEFEAT Cancer** data capture forms, one (a 1-month form) that allowed more types of activity to be recorded than the other (a 2-month form). The forms were returned to **DEFEAT** staff for tabulation (see Goal 4).

Every-Other-Week: A hiking program occurred every other week between May 1 and September 15 that started with flat hikes along rivers, progressed to treks in the Cascade foothills, increased to climbs on glaciers and 8000-9000 foot peaks, and culminated in a successful ascent to the highest peak in central Oregon, South Sister, elevation 10,320 ft. Fifty-five **DEFEAT** participants started the 4900 ft elevation climbed between 6 and 7 am and more than 25 reached the summit in what for most was a 10-11 hour round-trip effort.

Monthly: Each month except December, a 2-hour evening session was held for participants that featured either experts on exercise and physical medicine (*Meet-the-Expert* quarterly sessions) or a regular session during which one hour was devoted to physical activity that included a speaker and/or physical exercise. A monthly issue of **E&N News** (March 2008 issue in Appendix 4) of current peer-reviewed medical literature and expert commentary from reliable media sources, compiled and annotated by Dr. Bleyer, is distributed and briefly discussed at each session. The monthly reviews are also posted on **DEFEAT**'s website and those LAF Community Programs grantees who signed up for the newsletter are notified.

Annual Retreat

During this 3-day weekend, every survivor and family member was able to participate in one or more of the following: hiking (this 6-hour round trip ascended 3-Fingered Jack), bicycling, canoeing, kayaking, volleyball, swimming, yoga, and Tai-Chi. Dr. Steven Kornfeld, head medical oncologist at the largest medical clinic in Central Oregon, attended and answered questions of participants that included the role of exercise in cancer survival.

www.defeatcancer.info provides additional information on this goal

Goal 2: **Nutrition**

Year-Round Program

Daily: Each participant was provided with either a 1- or 2-month **DEFEAT** data capture form (described above) on which daily consumption of fruits and vegetables were recorded. The forms were returned to **DEFEAT** staff for tabulation (cf. Goal 4).

Monthly: Each month except December, a 2-hour evening session was held for participants that featured either experts on nutrition and meal preparation (*Meet-the-Expert* quarterly sessions) or a regular session during which one hour was devoted to physical activity that included a speaker and/or food demonstration. Each session included a meal selected by cancer nutritionist expert Carol Schrader. The meals were used to demonstrate how excellence in nutrition, good taste, and gourmet preparation can be combined in a relatively inexpensive and synergistic manner. A monthly issue of **E&N News** (March 2008 issue in Appendix 4) of current peer-reviewed medical literature and expert commentary from reliable media sources, compiled and annotated by Dr. Bleyer, is distributed and briefly discussed at each session. The monthly reviews are also posted on **DEFEAT**'s website and those LAF Community Programs grantees who signed up for the newsletter are notified.

Annual Retreat

During this 3-day weekend, nutrition and food preparation lessons, recipe comparison, and food demonstrations were conducted. Smoothies and campfire delectables of high nutritional value were provided. As mentioned above, Dr. Kornfeld, medical oncologist, answered questions of participants that included the role of nutrition in cancer survival.

www.defeatcancer.info provides additional information on this goal

Goal 3: Not scheduled for Year 1

Goal 4: Improve Quality of Life

Year-Round Program

SF-36 Results and Plan. The year-round program is designed to facilitate activities and fulfillment of daily living. In order to assess the failure or success of this objective, the SF-36 Quality of Life (QOL) evaluation was obtained and provided to each **DEFEAT** participant (cf. Goal 4). Eighty forms were completed and returned for analysis. The initial results (year 1) will serve as a baseline assessment for evaluation of **DEFEAT**'s current program in helping survivors and the caretakers improve their QOL. All of the 80 SF-36 baseline scores have been tabulated for each of the 8 major components (general health, emotional health, mental health, physical functioning, physical role, bodily pain, vitality, social functioning) (Table). The mean (\pm SD) scores for the physical and mental component summaries were 47.8 (8.7) and 50.3 (9.5), respectively. The lower mean physical summary score was due primarily to a low physical functioning score of 45.2 (10.2), indicating a need to focus on improving physical ability if QOL is to substantively improve.

DEFEAT Cancer SF-36 Results

	NBS: Norm Based Scores								Summary Scores	
	PF	RP	BP	GH	VT	SF	RE	MH	PCS	MCS
	Physical Functioning	Role Physical	Bodily Pain	General Health	Vitality	Social Functioning	Role Emotional	Mental Health	Physical Component Summary	Mental Component Summary
N	80	80	80	79	79	80	80	79	79	79
Mean	48.4	45.2	49.3	50.7	51.7	47.6	47.7	51.2	47.8	50.3
SD	9.5	10.2	9.2	7.6	9.2	10.4	10.5	9.1	8.7	9.5

Program-Specific Evaluation. In addition, a **DEFEAT**-specific evaluation form was developed by our new Survivorship Coordinator, Beth Larsen, and piloted on 29 non-selected participants. The results are tabulated in Appendix 1 and document the need for a program like **DEFEAT** to help improve QOL during and after cancer for both the survivor and caretaker.

Participant Interest Survey. Another form was developed to determine each participant's specific exercise and nutrition interests and completed by 33 non-selected **DEFEAT** participants. The initial survey results (Appendix 2) indicate a broad interest in physical activities and more limited but clear interest in nutrition topics. The plan to obtain a broader sample and thereafter restructure E&N sessions accordingly and to form groups (teams) of common interest for a year-old training program that culminates in a major annual event (viz. climbing to the top of South Sister last year).

Annual Retreat

The results are tabulated in Appendix 3 and document the value of the Retreat in promoting QOL for a weekend and, given that the questionnaire was completed by many participants several weeks after the Retreat, for some time thereafter.

Goal 5: **Individual and Collective Progress**

The daily physical activity and consumption of vegetables and fruits were entered into a database by one of the **DEFEAT** volunteers (rectal cancer with multiple complications, son in Iraq). The results were analyzed by Dr. Bleyer and each participant's data were provided confidentially to the participant. The collective progress was collated and considered as a baseline in year 1 for progress determination in years 2 and 3.

Goal 6: Not scheduled for Year 1

4.) Describe any activities yet to be completed.

Activities that were planned for Years 2 and 3

Goal 3: **Sustain Life-Style Objectives**

Year-Round Program

Cumulative vegetable/fruit consumption and exercise activities, including steps taken, show sustained trends into year 2 by those survivors who participate in both years 1 and 2

Annual Retreat

Under leadership of last years' Co-Chairs and a sizable Retreat Committee, an in-depth review of the Retreat program is in progress. Special sessions on nutrition, cooking and food preparation, physical exercise (hiking, swimming, volleyball, bicycling, bird watching), yoga, expressive writing, stress management, and relaxation techniques (crafts), as well as an oncologist question-and-answer session will be held again, along with new exercise and nutrition sessions.

Goal 6: **Outreach**

Year-Round Program

The rural proportion of participants is expected to increase 20% over the number participating in year 1. At least 5 Native American survivors are planned to be registered, with 3 regularly attending **E&Nergy** sessions via interactive broadcasts and submission of **E&Nergy** data via mail

A young adult subprogram is expected to actively engage survivors between 10 and 40 years of age.

Annual Retreat

Since the Retreat site is in the Cascade Mountains that divide Central and Western Oregon, the plan is to accrue cancer survivors from cities on the other side of the mountain range: Eugene, Corvallis, Salem, etc.

5.) Discuss any challenges or barriers encountered thus far and the strategies that have been or will be used to overcome them.

1) There are approximately 8500 cancer survivors who live in the wide geographical region of central and eastern Oregon. **DEFEAT Cancer** has registered 300 of them. To **increase participation**, we plan to extend coverage of our monthly sessions to remote sites via live interactive broadcasts to other hospitals and clinics and to homes via the internet.

2) Our attendance at the monthly evening sessions averaged 45 survivors and spouses, with a range of 33 (winter storm) to 60+. On one hand the attendance did not grow during

the year and on the other our meal budget was exceeded. The challenge is to **increase the onsite attendance** and also to **secure additional funding** or seek alternative solutions to serving full meals and yet maintain the nutrition component of our live program. A sponsor for the nutrition program, Advanced Specialty Care, was solicited for support, which was successfully secured for year 2 in January, 2008.

3) Few participants join **DEFEAT** during active cancer therapy; they enroll after treatment is completed. **DEFEAT's** goal is to **accrue cancer patients early in therapy**, shortly after diagnosis, before less optimal habits as a cancer survivor are established. Advanced Specialty Care, representing five surgeons, four physician assistants, and their own nutrition program (bariatric surgery) has agreed to refer patients as soon as they are diagnosed. The largest specialty clinic in Central and Eastern Oregon, an initial co-sponsor, will be approached for the same purpose.

4) The average **DEFEAT** participant attends 3-4 monthly sessions and the summer Retreat. **Turnover** is significant with new members balanced by attrition. We favor more sustainability and will attempt to lengthen the average participation, notwithstanding the possibility that what the average participant needs from **DEFEAT** can be learned in a few sessions. Serial QOL assessments with the SF-36 instrument may help assess the need.

5) Our **QOL consultant**, David Osaba, BSC, MD, at the University of British Columbia, suffered health problems during the year that prevent his participation. With the help of Brad Pollock, Ph.D. of the University of Texas Health Sciences Center at San Antonio, we are seeking another expert. Dr. Pollock was our resource in the interim (he suggested the SF-36 instrument for Goal 4). Alternatively, Dr. Bleyer should be able to fulfill the need for most purposes since he utilized a variety of QOL instruments in several adult cancer clinical trials during his 5-year directorship of the M.D. Anderson Community Oncology Research Base. .

6) **DEFEAT Cancer Advisory Board**. To help resolve issues 1-4, we have formed an Advisory Board of nine of our most active and wise participants via an open nominating process (self-referred and external) and selection by the DEFEAT Cancer Steering Committee. The Board has met twice and is undergoing an active strategic and long range planning process.

6.) Explain any variance from the original goals and objectives and timeline.

The Advisory Board (see 6 above) will thoroughly reassess the program, and build on the experience and lessons to date. Pending the Board's input, no substantial immediate differences are anticipated in original the goals and objectives. The tactics and organizational support to accomplish the goals are expected to significantly evolve, however, based on the Advisory Board's recommendations, during Year 2.

7.) Actual number of individual participants being served directly by this project to date:

To date, the following persons have been registered and potentially available:

	Registered	Available
Patients Survivors:	246	210
Spouses	<u>105</u>	<u>83</u>
Total	341	303

More than 100 survivors, family members and staff spent a weekend in August 2007 at the Soaring Spirits Retreat and Refresher Course.

8.) If the actual number is less that the projected number, how do you plan to reach the projected number?

The actual number exceeded the projected number.

9.) If you will not be able to reach the projected number or individual participants please describe why.

The first year was successful in reaching a targeted number of participants. The potential role of the program as a national model, however, merits expanded horizons.

Instructions for Q-10 -13:

Since your application was accepted, the Lance Armstrong Foundation has changed the requirements for reporting and we would like to collect additional information about your program, if you are currently collecting the data listed below. If you are not currently collecting the information listed below, please leave this section blank.

10.) Identify the population(s) directly served by this project; check all that apply.

Served	Category
<input checked="" type="checkbox"/>	Pediatric (0-14) viz. weekend physical activities (hikes, etc) and the Retreat for families
<input checked="" type="checkbox"/>	Adolescents/Young Adults (15-39)
<input checked="" type="checkbox"/>	Adult (40-65)
<input checked="" type="checkbox"/>	Older Adult (65+)
<input checked="" type="checkbox"/>	Individuals who have cancer or are managing cancer as a chronic illness
<input checked="" type="checkbox"/>	Individuals who had cancer but are no longer receiving active treatment
<input checked="" type="checkbox"/>	Family Member, Spouse, Partner or Other loved ones of people who have or had cancer
<input checked="" type="checkbox"/>	Siblings of people who have or had cancer
<input checked="" type="checkbox"/>	Family Member, Spouse, Partner, Other Loved Ones who have lost someone to cancer
<input checked="" type="checkbox"/>	Caregiver (Family Member or Friend) of people who have or had cancer
<input checked="" type="checkbox"/>	Medical or Nursing Providers in the Cancer Community
<input checked="" type="checkbox"/>	Other health professionals (emotional, social or educational) in the Cancer Community
<input checked="" type="checkbox"/>	Individuals that live in urban areas
<input checked="" type="checkbox"/>	Individuals that live in rural areas
<input checked="" type="checkbox"/>	American Indian or Alaskan Native
<input checked="" type="checkbox"/>	Asian
<input checked="" type="checkbox"/>	Black or African American
<input type="checkbox"/>	Native Hawaiian or Other Pacific Islander
<input checked="" type="checkbox"/>	White
<input checked="" type="checkbox"/>	Other Racial/Ethnic Groups (Please List) Hispanic Latino
<input checked="" type="checkbox"/>	All Cancer Types
<input checked="" type="checkbox"/>	Specific Cancer Types (Please list) -- Survivors of any cancers and their personal caregivers are able to participate. Current representative cancers are of the breast (including male breast), prostate, colon, rectum, anus, esophagus, stomach, small intestine (carcinoid), pancreas, lung, kidney, thyroid, ovary, cervix, testis, skin (melanoma), lip, larynx, throat, urethra, bladder, brain, peripheral nerve (sarcoma), muscle (rhabdomyosarcoma), hematopoietic system (lymphoma, myelodysplasia)
<input type="checkbox"/>	Other Populations (Please describe below)

11) Percentage of total number served in this project in the following priority populations:

- 1 % African-Americans
- 5 % American Indian/Alaskan Native
- 3 % Asian/Pacific Islanders
- 5 % Hispanic/Latino populations
- 0 % Hawaiian/Pacific Islanders

12.) Percentage of total number served in this project in the following age categories:

0 % Pediatric (0-14)
14 % Adolescents/Young Adults (15-39)
66 % Adult (40-65)
20 % Older Adult (65+)

Median Age (Years)	56
Youngest (Years)	15
Oldest (Years)	80
Age <40 Years	14%
Age >60 Years	25%

13.) Percentage of total number served in this project in the following categories:

30 % Rural Populations
70 % Urban Populations
30 % Low-socio-economic strata

14.) Please include any client stories or quotes you may have collected that you feel reflect the impact of this project.

See Appendices 1, 2 and 3

15.) Are you currently receiving funding from other groups to support this or similar projects?

Our parent institution is underwriting the costs of **DEFEAT Cancer** that are not covered by the Lance Armstrong Foundation Community Program Grant. This amount was anticipated at the beginning of the year to be \$38,658 but the actual amount is being estimated to be considerably less.

16.) As a part of this project have any of the following LAF tools, resources or programs been utilized?

- LIVESTRONG™** Notebook
- LIVESTRONG** Educational Resource Online
- LIVESTRONG** Survivor*Care*
- LIVESTRONG** Advocacy Team
- Living After Cancer Treatment Brochure Series

17.) Do you have any need for technical assistance from the LAF at this time? If so, please describe your needs.

So far, so good.

Appendix 1

DEFEAT Cancer PROGRAM SURVEY & EVALUATION

RESULTS

August 14, 2007

We're half-way through our Lance Armstrong Foundation grant year and want to make sure we're on track. Our goal is to work with you to co-create a model program for cancer survivorship, to give you what you need to start down and stay on a healing path. So, please don't be shy! We need your thoughtful and candid feedback about our monthly meetings.

All questions are general inquiries re: DEFEAT sessions that you attended since April, 2007.

We'll start asking similar questions on a regular basis so that we can respond more quickly to your needs.

Please use this rating scale: 5=Excellent 4=Good 3=Neutral 2=Fair 1=Poor

Purple is highest rating in category

*** are additional comments written in by respondents**

1. Communication and registration

Pre-meeting notices and communications

5 – 86% (19/22) [19 out of 22 responses]

** much improved*

4 – 9% (2/22)

3 – 5% (1/22)

b. Meeting registration

5 – 74% (17/23)

4 – 26% (6/23)

**always friendly*

c. Hand-outs

5 – 87% (20/23)

4 – 9% (2/23)

3 – 4% (1/23)

Comments and recommendations:

- *I love the up-to-date research handout.*
- *Non-breast cancer patients don't seem to be aware of any programs.*
- *Some persons new to our area are not aware either. I have been trying to let people know when I find them.*

2. Nutrition

a. Monthly dinners – taste

5 – 87% (20/23)

4 – 13% (3/23)

b. Monthly dinners – variety

5 – 83% (19/23)

4 – 17% (4/23)

c. **Amount of nutrition information received**

5 – 36% (8/22)

**We can always use more/refreshers*

4 – 55% (12/22)

3 – 9% (2/22)

d. **Do-ability of nutrition suggestions**

5 – 38% (8/21)

4 – 62% (13/21)

**We need the bachelor's version*

- e. Nutrition inspiration (ie. When you leave each meeting, are you inspired to eat more nutritiously?)

5 – 82% (18/22)

4 – 18% (4/22)

- f. **Follow-through on nutrition goals (ie. The month after a meeting, are you able to meet your nutrition goals?)**

5 – 0

4 – 73% (16/22)

3 – 23% (5/22)

**My goals are near perfection. Haven't met them.*

2 – 0

1 – 4% (1/22)

**Haven't made any goals*

- g. **Leadership with friends and family (ie. Because you're taking a more active role in your health, are you able to positively influence your family or friends?)**

5 – 23% (5/22)

4 – 59% (13/22)

3 – 18% (4/22)

Comments and recommendations:

- *I am actively trying to eat better and lose weight.*
 - *July demo not too helpful. Vague enough to sell the class.*
 - *I'm excited about the recipe book.*
 - *Because the focus is on E&N, I can "pump" the program to family & friends who are dealing with cancer.*
 - *Would love some of the recipes*

3. Physical Activity/Exercise

- a. **Meeting exercise – variety**

5 – 29% (6/21)

4 – 52% (11/21)

3 – 19% (4/21)

- b. Meeting exercise – challenge level

5 – 43% (9/21)

4 – 19% (4/21)

3 – 33% (7/21)

not high enough – 5% (1/21) [this was a write-in]

**I realize that the spread of physical abilities limits what can be done; it points in the right direction, however.*

- c. Do-ability of exercise

5 – 80% (16/20)

4 – 10% (2/20)

3 – 10% (2/20)

**I'm not able to do most of these exercises.*

- d. Exercise recommendations received

5 – 50% (10/20)

4 – 50% (10/20)

- e. Exercise inspiration (ie. When you leave the meetings, are you inspired to be more physically active?)

5 – 59% (13/22)

** Absolutely*

4 – 41% (9/22)

- f. **Follow-through on exercise goals (ie. During the month after a meeting, are you able to meet your physical activity goals?)**

- 5 – 27% (6/22)
4 – 59% (13/22)
 3 – 9% (2/22)
 *Still having operations
 *Having a tough time dedicating regular time.
 2 – 5% (1/22)

- g. **Leadership with friends and family (ie. Because you're taking a more active role in your health, are you able to positively influence your family or friends?)**
 5 – 27% (6/22)
4 – 50% (11/22)
 3 – 18% (4/22)
 2 – 0%
 1 – 5% (1/22)

Comments and recommendations:

- *I have now increased exercise.*
- *Meet the experts especially helpful for individual help & goal setting*
- *I'm realizing more & more the importance of exercise.*

4. Peer-reviewed cancer research and media

- a. Interest in articles reviewed
5 – 48% (11/23)
 4 – 39% (9/23)
 3 – 13% (3/23)
- b. **Discussion time allotted to review literature**
 5 – 23% (5/22)
 4 – 32% (7/22)
3 – 41% (9/22)
 *could spend longer
 2 – 4% (1/22)
- c. Interpretation provided to help understand reports
5 – 43% (9/21)
 *Carol, Archie & others views are wonderful.
4 – 43% (9/21)
 3 – 14% (3/21)
- d. **Relevance of survivorship research and data to your personal needs**
 5 – 33% (7/21)
4 – 62% (13/21)
 3 – 5% (1/21)
 *usually not to my cancer

Comments and recommendations:

- *I really am thankful this program exists. It's into health and surviving and not "poor me." Wish more time was available.*
- *This is my favorite part.*
- *Let's talk more about research on surviving cancer.*
- *I like it when Archie reviews the articles.*
- *Getting good filtered peer reviewed information translated by professionals & friends is wonderful.*
- *Need more men's issues discussed (e.g., prostate cancer)*

5. Meet the Expert

- a. Variety of topics offered
5 – 67% (14/21)
**this last session in particular*
 4 – 33% (7/21)
- b. Interest in topics offered
5 – 81% (17/21)
 4 – 19% (4/21)
- c. Expertise of experts
5 – 95% (20/21)
 4 – 5% (1/21)
- d. Quality of experts' advice
5 – 95% (20/21)
 4 – 5% (1/21)
- e. Relevance of presentation to your survivorship needs
5 – 55% (6/11)
 4 – 45% (5/11)

Comments and recommendations:

- *Wish longer cycles but understand time is an issue.*
- *I would prefer these experts to make a presentation or short intro/presentation followed by lots of discussion questions & answers.*

6. Documentation

- a. Availability of the E&N Data Forms
5 – 88% (16/18)
 4 – 6% (1/18)
 3 – 6% (1/18)
- b. Usability of the E&N Data Forms
5 – 72% (13/18)
 4 – 22% (4/18)
 3 – 6% (1/18)

Comments and recommendations:

- *I just need to do it for you!*
- *The abbreviated form doesn't have enough room in the other exercise column.*
- *Put E&N recording sheet on-line so we can print them off when we need a new one.*
- *Review each time what constitutes a serving & how to tally the daily intake.*
- *I'm concerned the one form that only counts total portions vs. portions spread throughout the day will encourage us to eat too much too infrequently vs. multiple smaller meals/snacks.*

7. Meeting Times and Dates

- a. How often do family members/friends attend DEFEAT meetings with you?
 Always – 5% (1/22) [this was a write in]
Frequently – 50% (11/22)
 Occasionally – 9% (2/22)
 Never – 36% (8/22)
- b. Is Tuesday evening a good day of the week for you to attend meetings?
Yes – 100% (23/23)
**not Wednesdays*
**Tuesday usually OK*
- c. Would a daytime meeting be more suitable
 Yes – 10% (2/21)
No – 86% (18/21)

Maybe – 4% (1/21) [this was a write in]

**No- I work and wouldn't be able to attend.*

**No-Having a dinner which shows what good nutrition looks like is important.*

**Yes-early afternoon.*

**Yes-especially during winters.*

**Maybe*

**Maybe*

d. What do you think about Saturday morning meetings?

Good idea – 0% (0/23)

OK, but not preferred – 52% (12/23)

No way – 48% (11/23)

**would not be able to attend*

e. Is transportation a problem for you?

Yes – 0% (0/22)

No – 100% (22/22)

8. What do you like *best* about the meetings?

- *Availability of information*
- *The inspiration I receive!*
- *Uplifting – Education*
- *Survivors surviving together*
- *Good ideas, encouragement*
- *Optimistic outlook, can do attitude, encouragement to act (diet & exercise), increased quality of my life.*
- *Positive attitudes.*
- *Nutrition information.*
- *New research data and food.*
- *Nutrition, information – medical*
- *Variety of subjects and a variety of ideas on improving diet & exercise*
- *Talking with people in similar positions; encouragement and inspiration of leaders.*
- *The research, the attendees, the programs, the speakers.*
- *Meeting others who have been through cancer journey; meeting staff who can support our ongoing needs.*
- *Archie! Food! Exercise! Inspiration! Fellowship!*
- *I am in contact with people who face similar challenges; who understand that I don't know what the future will be – say six months from now.*
- *Camaraderie, info, great food, encourage.*
- *Visiting with survivors, sampling new foods, positive encouragement, research reviews.*
- *The speakers & camaraderie.*
- *The food, the info & the other people.*
- *Encouragement for nutrition & exercise (& ideas!). Information about surviving & quality of living as a survivor & positive environment ☺*

9. What do you like *least* about the meetings?

- *Not long enough*
- *Nothing*
- *Nothing*
- *Multi-tasking, trying to track all meeting input at once*
- *Can't think of any*
- *Nothing*
- *Sometimes there is so much to cover I feel we only get a brief glimpse of the info.*
- *It is all good.*
- *Time pressure of trying to get so much into a 2-hour time restriction.*
- *They come to an end!*
- *Trouble with technology*
- *I've been to two meetings and two hikes – it's too soon to tackle this one.*
- *The organization was a bit confusing at first. It now seems to roll along.*
- *I like them all*

10. What activities or presentations would you like to see at future meetings?

- *More nutrition info*
- *Always have a beginner or intermediate program along with advanced.*
- *Exercise & maybe diet planned program such as Joan Gould Ashes Spread. Winter snowshoeing?*
- *More demonstrations of cooking and food products that aren't commonly used, like the cooking grains demo.*
- *Speakers*
- *Would enjoy hearing Dr. Bleyer discuss Lance Armstrong's case and treatment.*
- *Complementary therapy representatives*
- *Recipes of the food served each month, please!*
- *Cooking demo, stress reducing activity –chi kung/Tai Chi/gentle yoga, what to do to avoid exercise injury.*
- *More study results*
- *Presentation or articles maybe prostate survivor issues.*
- *I'm interested in continuing beyond the South Sister hikes. Snowshoes, for example.*

11. Remote Broadcasting

- a. Do you know that we are now broadcasting our evening sessions to Redmond and Warm Springs?

Yes – 91% (21/23)

No – 9% (2/23)

- b. *If we were able to live-stream our sessions on the internet (broadcast on the internet in real time), would that be helpful/of interest to you?*

Yes – 39% (9/23)

No – 61% (14/23)

Comments:

- *No-I like the face-to-face personal meetings.*
- *No-doesn't matter*
- *Yes-I'd love to get this monthly meeting when we are in our winter home of Tucson.*
- *Yes-Very helpful for us as we go to Arizona for the winter and then we could stay involved. It is unfortunate that Tucson, Arizona does not have a similar program.*
- *Yes-I could have my sister in Portland tune in.*
- *Yes, but my tin can & string ISP connection is too slow.*

12. Do you know what LiveStrong refers to?

Yes – 96% (22/23)

No – 4% (1/23)

13. Will you attend DEFEAT meetings again?

Yes – 100% (23/23)

*Yes – you bet!

Additional Comments

- *I would like to carry DEFEAT "business cards" to share in BMC infusion room as I meet other cancer survivors in chemo.*
- *I now use grains I've never ate before because of the demo by Lisa showing us ideas and the literature I took home telling me how to cook them. Thank you so much for this program!*
- *Thank you to everyone involved in bringing these meetings to us!
What an outstanding program!*
- *THANK Y@U!*

Appendix 2

DEFEAT Cancer Participant *Exercise & Nutrition* Interest Survey

February 12, 2008

Total responses – 36

Currently, I:

Walk daily	24
Walk Occasionally	12
Run	8
Hike	19
Bike	15
Kayak	5
Play golf	5
Play Tennis	1
Rock climb	0
Ski	11
Cross Country Ski	2
Swim	4
Snowboard	0
Snowshoe	11
Fish	9
Exercise at a gym	21
Power yoga	2
Canoe	1
Surf	1

I would like to train for:

Heaven Can Wait	17
Tour des Chutes	12
Mt. Bachelor	19
Chef Cookoff	5
Climb Mt. Rainier	1

I would like to learn more about:

Nutrition/health eating - general	18
Healthy cooking	16
BMI/health relationship	9
Research/peer reviewed lit	12
Vegetarian cooking	1
Rose's writing workshop	2

I would like to lead a team:

Participant PVC	flexible
Participant RW	healthy cooking
Participant AJ	healthy cooking
Participant CF	flexible

I would like to learn how to:

Walk regularly	7
Run	0
Hike	5
Bike	4
Kayak	7
Play golf	3
Play tennis	2
Rock climb	2
Sik	0
Snowboard	1
Snowshoe	12
Fish	3
Exercise at a gym	5
Skydive	1
Strength training	1

Additional comments:

Continue to challenge us with exercise & diet. It is encouraging.	Increase time on review of literature
Basic, basic, basic food/nutrition/exercise for novices!	More exercise demonstrations
Speakers for support groups	Monthly hikes-they were great!
I like special speakers. Very encouraging.	Volunteer research program
Some folks may be interested in swimming, fishing, etc.	Have presentation on sleep, fear, hygiene control
I am concerned about the stress caregivers go through and families with kids	Include support group format
	More of same

Also, some of our folks who are alone on their journey may be finding ways we can all be more support and encouragement to hang in there and stay involved with DEFEAT
Sometimes I think I wish I could learn more but then my brain gets too full!

Appendix 3

DEFEAT Cancer Retreat Program Evaluation, Soaring Sprits 2007

Rating scale: 5=Excellent 4=Good 3=Neutral 2=Fair 1=Poor

*BLUE is highest rating in category; * are additional comments written in by respondents
Total of 34 evaluations returned*

1. Pre-Retreat information and communication

5 – 67% (22/33)

4 – 30% (10/33)

3 – 3% (1/33)

Comments and recommendations:

- Add a check-box for vegetarian, food allergies, sensitivities. Does the registration form tally # and ages of the kids?
- Information came late
- Received the mail info a bit late (Thursday)
- Excellent response for a “last minute” participant.
- Did not see.
- Directions at the lake and accurate name of turn off from highway.
- Grate food all week
- Please be aware that not everyone has capability to print from their email. Would have been very helpful in planning to have had a hard copy of schedule in the mail a week ahead of time.

2. Day 1

a. Registration

5 – 84% (26/31)

4 – 16% (5/31)

b. Dinner

5 – 75% (24/32)

4 – 19% (6/32)

3 – 6% (2/32)

*need a non-beef option and/or veg

c. Q&A with Dr. Kornfeld

5 – 79% (22/28)

4 – 18% (5/28)

d. Campfire Entertainment

5 – 68% (21/31)

4 – 26% (8/31)

3 – 3% (1/31)

2 – 3% (1/31)

Comments and recommendations:

- Having people to help with bags was great. Wonderful welcoming committee all the way around. Steve was so good and so nice to give out a CD.
- Arrived a little late, so things had been packed up, but Marlys helped us get the welcome info.
- Campfire-snack for kids before entertainment would have been helpful.
- Enjoyment was impacted by the sparks of the fire– concern for fire but we were safe.
- Just great!
- More vegetables! The vegetarian selection was just so-so. Meatloaf & gravy not too healthy.
- S’mores at campfire please ☺

3. Day 2

a. Breakfast **5 – 85% (28/33)**

- 4 – 15% (5/33)
- b. Lunch **5 – 82% (27/33)**
4 – 18% (6/33)
- c. Dinner **5 – 74% (25/34)**
4 – 23% (8/34)
3 – 3% (1/34)
- d. Campfire Entertainment
5 – 94% (30/32)
4 – 6% (2/32)

Comments and recommendations:

- Have him [Kip Attaway] next year.
- Dr. Bleyer was a 10!
- What a wonderful day! Just the correct mix of structure and free time. Too many fun things to do.
- Food was excellent.
- Sack lunch idea/selection for hikers was great.
- Great day! Massage & fishing filled up fast! Missed out on some things but still plenty to do.
- The variety of activities were incredible! Meals were all wonderful. The staff so kind and available at all times.
- Kip Attaway was a joy!! Lots of laughter – with a backdrop of campfire & pines!!
- Staff did a great job of accommodating my allergies. Kip Attaway was really great.
- Thanks for letting us do marshmallows with the kids before the entertainment. My kids loved the birdhouses & fishing on the boat!!!
- Lunch was GREAT. 10 for entertainment.
- Walk around the lake took about 2 hours, rather than one.
- The entertainment was terrific up to a point! Love to have him back, but a little edited. (the last song wasn't appropriate for older/younger)
- Kip was superb! Kip was wonderful!
- Kip Attaway was amazing.
- And I got to plant a plant.
- The food was excellent offering lots of choices – Entertainment outstanding!
- “Excellent” in all areas – comfortable.
- Kip was funny

4. Day 3

- a. Breakfast **5 – 90% (26/29)**
4 – 3% (1/29)
3 – 7% (2/29)
- b. Memorial **5 – 100% (14/14)**
- c. Spiritual **5 – 92% (12/13)**
Service 4 – 8% (1/13)

Comments and recommendations:

- Great!
- Not attend – had to be at my church.
- Eggs bad. I don't like eggs.
- Learned a lot. Loved the crafts.
- Tree planting was Great!

5. All Activities

What activities did you and/or your family participate in over the weekend?

- a. Tai Chi Meditation
5 – 100% (6/6)
- b. Exercise with Therabands
5 – 100% (5/5)
- c. Children's Activities
5 – 71% (5/7)

- 4 – 29% (2/7)
- d. Guided Hike to Canyon Creek Meadows
5 – 100% (10/10)
- e. Reiki & Massage
5 – 92% (11/12)
1 – 8% (1/12)
- f. Crafts **5 – 90% (17/19)**
4 – 10% (2/19)
- g. Fishing **5 – 100% (5/5)**
- h. Self-guided Hiking
5 – 91% (10/11)
4 – 9% (1/11)
- i. Biking **5 – 83% (5/6)**
4 -- 0%
3 – 17% (1/6)
- j. Swimming **5 – 100% (1/1)**
- k. Canoeing **5 – 67% (4/6)**
4 – 33% (2/6)
- l. Kayaking **5 – 100% (2/2)**
- m. Bird Watching
5 – 75% (3/4)
4 – 25% (1/4)
- n. Challenge Course (cancelled due to non-participation)
- o. Guided Hike Around Suttle Lake
5 – 64% (7/11)
4 – 36% (4/11)
- p. Volleyball **5 – 67% (2/3)**
4 – 33% (1/3)
- q. Stretching **5 – 100% (3/3)**
- r. *Mending Words* Writing Workshop
5 – 50% (2/4)
4 – 25% (1/4)
3 – 0%
2 – 0%
1 – 25% (1/4)
- s. Nutrition Cooking Demo
5 – 83% (5/6)
4 – 0%
3 – 17% (1/6)
- t. Guided Relaxation
(cancelled due to scheduling problem)
- u. Other [write-ins]
Built birdhouses – 5
Plants were great! - 5
- v. Variety of Daytime Activities
5 – 88% (15/17)
*We ran out of time, but the choices were great
4 – 12% (2/17)
- w. Activities appropriate for all family members
5 – 75% (9/12)
4 – 25% (3/12)

What activities would you like to see at future retreats?

- Paddle boats
- More Reiki – it filled up too fast.

- Yoga? Pilates
- Repeat all of the above ☺ Add more massage/Reiki slots
- A guided meditation; using the labyrinth.
- Soccer
- Hiking, biking, kayaking, volleyball.
- I thought there were plenty
- The activities overlapped so it was hard to go to some. Maybe a schedule with activities set at consecutive intervals would be easier (?). More popular activities should be repeated.
- 2X the bird watching – or different times was conflict w/other activities.
- Yoga
- More teen stuff.
- More in-depth writing workshop, Bill Baker the Aussie Poet, The Cowboy Poet & Kip Attaway, more Massage and Reiki
- Geocaching would be an excellent activity.
- “Mending Words” needs a better description. Not “writing workshop”. Would like to see an actual writing workshop – teach survivors & families to write their “stories.”
- More Reiki & Massage please – class was full
- Yoga
- We would have liked to do the Challenge Course but people didn’t show up. Know how long the hike (Canyon Creek) will take approx. and communicate that with people so they won’t sign up for PM activities.
- Bill Baker, poet, to return
- Different length hikes – more fishing opportunities – More options for exercise/Tai Chi/ Reiki, etc.
- More massage, more meditation in keeping with “retreat” environment.

What activities would you eliminate?

- None
- Rain! (Gary Johnson says so!)
- None
- None – expand fishing, if possible
- None
- Wish I had time to try them all. Can’t give an opinion.

6. Camp Accommodations

5 – 38% (11/29)

4 – 55% (16/29)

3 – 7% (2/29)

Comments and recommendations:

- Stayed in Lodge – very comfortable.
- It’s fine for camp (no critters/insects/clean bathrooms & showers)
- They were fine for this type of setting.
- Keep up the great work!
- Great camping experience for my young family.
- Thank you for the fantastic accommodations!
- The cabins were very comfortable.
- Wesley quarters – quiet and comfort.
- More toilet paper on 1st floor in Wesley female
- Cabins have improved.
- Great!
- Just need a chair or two in each cabin.

7. Did you and/or your family benefit from attending the Soaring Spirits Retreat

Yes – 100% (22/22)

No – 0% (0/22)

8. Indicate what you found most valuable about the Retreat. (check as many as you wish)

[Ranked in order of preference; 34 surveys returned]

1. (tie) Location (venue) – 28
1. (tie) Soaring Spirits Staff – 28
3. (tie) Camaraderie (new friends/time with old friends) – 24
3. (tie) Campfires & Entertainment – 24
5. Variety of Activities – 21
6. (tie) Meals – 19
6. (tie) Campground Staff – 19
8. Price (fee) – 17
8. Oncologist Q&A (Friday night) – 16
10. Exercise Sessions – 11
11. Family Focus – 10
12. Spiritual & Memorial Service - 7
13. Nutrition Sessions – 6

What did you like best about the Retreat? Did you have a favorite moment or overarching feeling about the weekend?

- Friendships
- Crafts
- Campfires
- It was a safe and happy place for people who are facing or who have faced cancer.
- Loved Kip Atkins. BBQ was good. Thank you for making camping great for our family! ** The “babysitter girls” were absolutely wonderful. My girls adore them and wanted to be with them all the time. What angels!
- Favorite moment – looking around the campfire at all the smiles and laughter during Kip Ataway’s performance.
- People caring and caring people.
- Chance to connect with others of similar experience, and share experiences.
- Being with my family away from all the responsibilities I have at home (food, dishes, laundry, etc.) Watching my boys have a blast in the outdoors. Talking with other survivors and their families and stories.
- The staff for Soaring Spirits and the participants were and are my favorites.
- Being together.
- I got to plant a plant.
- All the activity choices. The chance to meet and get to know new people.
- Saturday night campfire with Kip.
- Getting acquainted with so many wonderful people.
- This was an excellent opportunity for me to get to know some of the people I’ve only been acquainted with through DEFEAT. It was a beautiful atmosphere and with lots of fun activities. Very relaxing.
- Connecting with fellow survivors and family – interacting, sharing, joy, hopes and futures.
- I loved Sat. night campfire – Attaway – WOW! ☺
- Friendship, (Kip Attaway) We want him back. Marlys was wonderful. Always fun and laughter around the campfire. *We want Bill Baker & family back!
- Hiking and meeting new friends – getting to know others better.
- Camaraderie & the time to relax among the tall trees with the wind whispering (& sometimes singing) in their branches.
- Being with my friend Elaine. Meeting people I’d like to know better & to spend time with. Kip Attaway. Tai Chi
- Friday campfire is great. (Do smores that night please!) ☺
- Great to network with other survivors and supporters.
- Campfire. Laid back atmosphere. Chance to try new things – reiki & massage & tai chi. Cookbook – thanks.
- The chance to get away and focus on relaxation and healing.

What did you like least about the Retreat?

- Rain
- None
- Weather
- Bunk beds (minor!)
- Can’t think of a thing!
- So many activities and so little time to do enough of them.

- That there wasn't a mixer to get to meet everyone.
- Beds
- Can't think of a thing
- Distance from our cabin to the bathrooms in the middle of the night.
- How activities overlapped so you couldn't do many things.
- Not too many young people.
- I couldn't do all of the activities ☺
- Communal bathrooms.
- Not much for teens to do.
- Not being able to participate in more activities because I did the hike to 3 Finger Jack.
- Loud women in AM on Sunday in Wesley
- Not enough activities for teens – really wanted to try challenge course.
- Weather didn't encourage water activities.
- Nothing
- Missing tacos on Saturday due to hike length.
- Seems almost too short.
- Not enough time

Are there any changes you'd recommend that you haven't mentioned anywhere above?

- Nope
- More non-beef food choices.
- None
- No
- Have the art stuff out a bit longer so that if we are doing activities from 9:45 – 12:00 or 1-3:30 we can do the crafts (t-shirts, bird houses, etc.) later (after dinner or before dinner)
- No
- I don't think so.
- None
- No
- None
- Repeat activities during day so we can schedule more events, activities.
- Nope
- More available room for massage/Reiki, etc.

9. Will you implement a lifestyle change as a result of the Retreat?

Yes – 86% (24/28)

No – 14% (4/28)

Please describe:

- Sharing more with my husband.
- Walk more
- More fruits & veggies, more exercise
- Try new recipes.
- Need to get out outside my shell some more.
- More camping after cancer.
- Exercises from Therabands class
- Pay more attention to healthier eating
- Reset priorities – more time to relax.
- I'm already changed so much from going through moms cancer.
- Keep the same
- Might pursue TiaChi
- More exercise
- Need more exercise
- Use more relaxation methods.
- I am trying!
- The retreat took me “out of myself,” guided me forwards to more interaction with the community as a whole.
- Activity level
- Be more creative.

- Exercise more – find places – safe to walk in nature
- LIVESTRONG!!

10. Would you like to attend Soaring Spirits again, as an annual event?

Yes – 100% (33/33)

*Definitely

*Even if I move

*This is our 3rd Retreat, so Yes!

No – 0% (0/33)

Any additional comments/thoughts/praises/inspiring anecdotes/ah-hah moments or other?

- Thanks again! -Carol Northrup
- Thank you from the bottom, middle and top of my heart to Dr. Bleyer, Marlys, and everyone else who participated in the planning and execution of this heartwarming, body exercising, instructional/informational, enjoyable weekend! St. Chas. has the greatest supply of gifted, caring, delightful staff right here at camp!
- Overall – a very nice experience!
- I was very impressed with the caring and friendliness of the Soaring Spirits staff. Great people!!
- It is so important for me as a cancer survivor to have caring support. My family is GREAT for this – it was a wonderful experience to have my family together to share this camp! Thank you to all who helped put this together & make this a great weekend – you are all amazing. The camp was very comfy & accommodating.

Appendix 4

DEFEAT Cancer E&N News – March 2008

Removed from Report

Available via www.defeatcancer.info, *Literature Review* in right lower square