

Constellation

A newsletter for all STAR participants



Meet The STAR Participant Advisory Board

These STAR participants were nominated by their clinical centers to represent the voice of all the women in the trial. These sixteen women were selected by the NSABP and the National Cancer Institute (NCI) from 50 nominations. They were chosen to represent numerous ages, races, ethnicities, and geographic locations. Their role is to provide the NSABP and the NCI leadership with feedback and suggestions to improve the conduct of the trial.



Jeannie Morice, Co-Chair
(Tom Baker Cancer Centre [TOM-01]; PC: Anita Hades)
Calgary, Alberta, Canada

To my closest friends, I am considered outgoing, fun-loving, and a little eccentric. I attribute all the above to my Irish Catholic upbringing. My Canadian-born husband Dale and I have survived 30 years of marriage with never a dull moment. Dale is a Scorpio and yours truly a Leo. We have three children, ages 24 to 28. Hopefully soon, we can enjoy the true meaning of "empty nesters." We love Calgary, Alberta and being close to the beautiful Rockies. My hobbies include wine making, tai chi, and walking my gorgeous golden retriever, Murphy.

I joined the BCPT, and now STAR, having lost my mother to breast cancer. I remain confident that the results of this trial will benefit not only myself, but my daughters and women everywhere.



Lonnie Williams, Co-Chair
(Integrus Oncology Services North/South [OKB-01]; PC: Lana Hale)
Oklahoma City, Oklahoma

I am a native Oklahoman. I have been married to the same man for 52 years. My hobbies are golf, aerobics, bridge, crossword puzzles, and reading. I have a bachelor's degree from Oklahoma State University and worked as a Service Representative for Southwestern Bell Telephone Company for 4 years after graduation. Since my children were born, my activities have been strictly volunteerism. These included various Parent-Teacher Association (PTA) offices, as well as president of our high school PTA. I spent 5 years on the Oklahoma City Symphony's woman's committee and 13 years as head of a box office committee for the Oklahoma City Lyric Theater. I was an active board member of the American Cancer Society for 15 years and am a member of the D.A.R. I also acted as an office manager once a week for my daughter's medical practice.

I became a BCPT participant in 1992 and was one of the first women to sign up for STAR, because my daughter, 35, was diagnosed with breast cancer while she was still in her medical residency and had a 5-month old baby at home. Until then, I hadn't been aware of how many young women got breast cancer and how devastating it was to the family. My daughter died in 1996 at the age of 42 of metastatic breast cancer. That is much too young to die. I was even more deeply committed to the prevention trial after her death. It is so important that we do something to prevent this from happening to our young women. I still have one daughter and one granddaughter about whom I am very concerned. From the beginning of the trial, I felt that I wanted to be a part of a program that was dedicated to the prevention of this terrible disease. If some way can be found to prevent this disease, I want to be part of it.



Grace del Castillo
(CCOP, Mount Sinai Medical Center [MIA-01]; PC: Franca Cenciarelli)
Miami, Florida

Grace joined STAR because she wanted to have an active role in the research for the prevention of breast cancer.

She was born in Cuba, and migrated to the United States at the age of seven. She is living in Miami, with her husband, her daughter and two sons. She has been a Telecommunications Service Consultant for

New inside this issue

- Meet the STAR Participant Advisory Board.....pages 1-4
- STAR Accrual Report.....page 2
- Reflections From Inside a Clinical Trial.....page 3

22,000 — Overall Goal

11,000 — July 2, 2001
Happy 2nd
Birthday, STAR!
Accrual was
10,473 and
more than
84,000 women
had their
breast cancer
risk assessed.

5,500 — June 30, 2000
Happy 1st
Birthday, STAR!
6,136 entered
STAR and
more than
47,000 women
had their
breast cancer
risk assessed.

2,750

July 1, 1999
Randomization
Began

Meet the PAB, [Cont. from page 1]

23 years. She is also the on air producer for her husband's sports radio broadcasts. She is fluent in both English and Spanish, and understands the importance of communication.

Grace became interested in STAR the minute she read an article about it in a local newspaper. Her younger sister had recently been diagnosed with breast cancer and had just completed her chemotherapy. Having seen the physical as well as the emotional effects of this horrible disease, she knows the important role that research plays in the fight to eliminate breast cancer. She feels that STAR has given her the opportunity of having an active part in the prevention of breast cancer, and she is very interested in spreading the word about STAR, especially among Hispanic women.



Evelyn Smith DeMille
(Dana-Farber Cancer Institute [DAN-01]; PC: Beth Cahoon)
Arlington, Massachusetts

An alumna of the BCPT, Evelyn enrolled in the trial in June of 1992 with a "desire to push the envelope in prevention, especially for breast cancer," says her STAR coordinator, Beth Cahoon. Evelyn's younger sister had been diagnosed with breast cancer five years earlier. Ironically, her sister died on the very day that Evelyn was told she had been accepted to participate in BCPT.

As one of Dana-Farber's first STAR participants, Evelyn strongly believes in the old adage, "an ounce of prevention is worth a pound of cure," and has a long-standing commitment to public health research. She wants to encourage other women to participate in breast cancer research, not only for themselves but also for their loved ones.

A social worker with public health training, she is currently the executive secretary of the Elizabeth and George L. Sanborn Foundation for the Treatment and Cure for Cancer. Evelyn, who is diabetic, has also worked for the Joslin Diabetes Center and Harvard University's Division of Health Policy Research and Education.

"[Evelyn] is extremely well informed on the most recent health information, particularly pertaining to cancer. She will bring her energy, creativity, commitment to prevention, excellent public speaking and organizational skills, as well as her experience in public health and public relations to the PAB," praises Cahoon.



Nancy Gent
(CCOP, St. Louis - Cape Girardeau [STL-01]; PC: Carol Antinora)
St. Louis, Missouri

"[Nancy] entered STAR based upon her primary goal in life... to help others," says her STAR site coordinator, Marian Wuest. Breast cancer had developed in both her mother and one of her sisters, which increased her desire to contribute to the research that might finally defeat this disease that devastates so many families. As a retired medical records administrator, "she passionately believes that medical science

cannot progress without [clinical trials]." Before she entered the STAR trial, she volunteered for and participated in many other clinical trials, both at the University of California at San Diego and at the Washington University School of Medicine in St. Louis, as well as at several medical research facilities in the St. Louis area.

"Her enthusiasm for STAR is contagious," continues Wuest. "She has already referred many women to the study and is credited for at least two new STAR participants since she began in January 2000." Nancy's most current goal is to encourage her older sister to participate in STAR with her since they share many of the same risk factors. Nancy's altruistic nature is apparent in her community efforts as well. She is currently working as a receptionist, caregiver, and driver for retired Ursuline nuns at their convent.



Gerri Groody
(CCOP, Santa Rosa Memorial Hospital [SRO-01]; PC: Janice Crouse)
Kelseyville, California

Gerri joined the STAR program to be on the cutting edge of the fight against breast cancer. After losing her mother to breast cancer and helping her sister in her own battle against the disease, Gerri felt the need to become further involved. While searching for information about reducing her risk of getting breast cancer, she came across the STAR program and the findings from the BCPT and decided to become a participant.

As the co-owner and producer of a San Francisco based syndication company and former art director for NBC News, Gerri is not a person to sit on the sidelines. Her STAR coordinator, Janet Crouse, says "She is a woman of action and involvement who believes that without women willing to commit themselves to research studies, there will be no new advances in breast cancer prevention."

Gerri has a long history of community involvement, including active participation in a San Francisco based outreach effort to the people of Nicaragua and The California Main Street Program and Sponsoring Survivorship, a breast cancer walk/run in Lakeport, California. She finds fulfillment in developing strong relationships among diverse groups of people and sees that as one of the biggest assets that she will bring to the program.



Ann Marie Gugger
(Fox Chase Cancer Center [FXC-01]; PC: Joan James)
Huntingdon Valley, Pennsylvania

My true occupation has evolved into being a Mom to my three sons, the result of twenty-eight years of a great marriage (most times anyway). I started off my adult life believing my career was to be a research chemist. This delusion lasted for sixteen years.

During these years of chemistry and raising a family, my mom developed breast cancer. I watched her die a slow but progressively demeaning death over a five year period. Working as a chemist during this time, I was able to use computer resources in their infancy and found there was not much available to us.

As I watched her die, I was determined to do whatever I could to prevent or detect the disease as early as possible. When I read a news blip about the original prevention study, I was very excited. I attended an information



session and was on my way. I have seen too many of my friends and family discover a lump and see the mental and physical anguish that follows. I know that I am in a position where I can do something to help others as well as myself and I plan on taking complete advantage of it.

I never had any doubt about participating in the first prevention study nor do I for the STAR trial. I waived my prerogative to take tamoxifen after the first study and waited for two years to be eligible for the STAR trial. I know that I am doing the best that I can for myself and other women.



Inola Highfill

(CCOP, Warren Cancer Research Foundation/Saint Francis Hospital [TUL-01]; PC: Nancy Bralic)
Tulsa, Oklahoma

With two sisters who succumbed to breast cancer and another who died from bone cancer, Inola has felt the devastating effects of the disease. "My family history of breast cancer resembles the game Dominoes...who will be the next to fall?" says Inola. But before cancer affected her family, she and her sisters were a popular gospel quartet for over 15 years whose performances included the yearly Tulsa State Fair and opening for such groups as "The Oakridge Boys," "Blackwood Brothers," and "The Statesman." Now Inola's talents have shifted to being an advocate for the prevention of breast cancer and STAR. As a Native American with strong family ties, she hopes to instill trust and help other women like her who may be battling with breast cancer within their own families. "The Lord has let me be free of this disease and I think it is my mission to prevent breast cancer in others," she says. In Tulsa, Inola was highlighted in a local television spot that is the first in a series of stories that will detail her experiences in STAR. "Inola is articulate and extremely comfortable with people and I think she will be an excellent PAB member," says her STAR coordinator, Nancy Bralic.



Judy Hupfeld

(University of Iowa Hospitals and Clinics [IOW-01]; PC: Mary Spaight)
Iowa City, Iowa

As a BCPT alumna, Judy's choice to participate in STAR was a natural evolution. She felt secure in the clinical trial setting and knew that she wanted to continue to play a part in something very important to her and other women. A former teacher, she has become a strong advocate for STAR and encourages other teachers in the local school system to seek information about the trial. "[Judy] is an excellent communicator, both as a speaker and writer, and has a great sense of humor in addition to a clear understanding of how important the clinical trial endeavor is in the fight against breast cancer," her STAR coordinator, Mary Spaight, praises.



Judith A. Jordan

(Univeristy of Texas MD Anderson Cancer Center [MDA-01]; PC: Edith Waller)
Houston, Texas

Judith's mother, grandmother, and great grandmother all battled breast cancer. She chose to take an active role in finding a way to prevent the disease and was the first BCPT

Reflections

From Inside a Clinical Trial

This issue's *Reflections* was submitted by Nancy Gent, a STAR PAB member from the St. Louis-Cape Girdeau CCOP in St. Louis, Missouri. She has given the NSABP permission to print this article in *Constellation*. The thoughts and words are her own and we thank her for sharing them with all of us. If you would like to share your experiences "from inside a clinical trial," please send your article to the NSABP (address available on back page) and you too may see your story highlighted in an upcoming issue of *Constellation*.

Since we had our first STAR Participant Advisory Board meeting in April and the STAR scientific meeting from June 2-5, I've been so energized I can hardly sleep. I want so badly for the rest of the "at risk" women to have the benefits of what a study can offer them that it's hard not to be excited.

On June 9, 2001 at 7 a.m., I joined 31,000 people in St. Louis, Missouri, who all had a similar goal — to fight, cure, or prevent breast cancer. Do you have any idea what 31,000 people look like in a group? It's larger than the population of the community where I live. That's a lot of people. With each person participating, we can make a huge difference.

When I arrived at the Susan G. Komen Race for the Cure® early that Saturday morning with three other friends, we were all excited and awestruck. One friend, quite a serious runner, preceded the rest of us, but we remaining three got caught up in the excitement. There was music, vocals, and prayers, and a local TV station was covering the event. All the co-sponsors of the Race had pitched tents and were giving away all kinds of helpful reminders, food, and — most precious — water. I was overwhelmed by the huge crowd, and the enthusiasm was electric.

There were people of all shapes and sizes: tall, short, little, big, heavy, skinny, adults, children, and even babies. People of all races, religions, and creeds showed up to participate in this event. There were the "serious" runners following the wheelchairs racers, then the joggers, the "serious walkers" (my group), and last, those who chose to do the one mile walk. It took an hour just for every participant to clear the starting line, not to mention that the winner finished 43 minutes before the last person started.

It was after the race began that my thoughts drifted inward. I began to notice just how many of the runners were wearing pink shorts instead of white ones to signify that they are breast cancer survivors. Then I noticed the pink signs pinned to the backs of the T-shirts, either in celebration of or in memory of someone dear, and in many cases, in celebration of oneself. I was

saddened that I hadn't gotten a sign to wear for my mother and sister — in celebration, not memory, happily enough. Well, I can do that next year. The most noticeable of all were the pink hair bobs sported by some 15 to 20 women who came to celebrate with a friend currently undergoing chemo therapy. These friends had come from as far away as California and Florida.

Five kilometers (3.1 miles) goes pretty quickly when you are caught up in the momentum of the Race. There was always water available and occasionally bands playing to help us keep up the rhythm of the moment. About two thirds into the Race, I broke from my friends and started on my own quest. It was then that I knew why I had come, why I would always participate, and why I would be forever grateful that I could do my small part to stop this disease from finding its way into the life of even one other person.

I became aware that directly in front of me was a group of people with sequential numbers beginning 22,801, 22,802, 22,803, 22,804, 22,805, 22,806, and 22,806½. There was a man at the beginning and a small boy at the end. In between were five beautiful girls ranging in age from early grade school to early high school. On the back of six shirts, the sign said, "in memory of my Mom," and on Dad's sign, it read, "in memory of my wife." I could have reduced myself to one large puddle at any instant. I was overcome with the magnitude and devastation of this disease. I wished I could give them all a hug and say, "this won't happen to you." I knew then that I was in this study to make those words come true.

We all joined the STAR study for different and very valid reasons. To be totally honest, the thought of "what's in it for me" did cross my mind, and was a big motivator. After all, I had seen what breast cancer had done to my sister, and then to my mother, and I sure didn't want it to happen to me. Being philanthropic, I have six beautiful nieces and three darling grand nieces that I also want to be spared from this disease. But it was numbers 22,801-22,806½ who gave true meaning to why I'm in the study. For me, it's clear, *it is the right thing to do.* ☆



...Continued on page 4

participant randomized at her site. When the BCPT ended, Judith, who had been on a placebo, had the option of beginning tamoxifen for the prevention of breast cancer, but she opted to wait and join STAR. Judith, who has two sons, hopes to help her nieces and other future generations find ways to decrease their breast cancer risk. "She has given of her time and talents freely and has been very active in promoting both trials," says her recommending coordinator, Diane Weber. "[Judith] has even appealed to a panel of physicians to identify all women at increased risk for breast cancer and make them aware of all available options to reduce their risk."



Heather Gracie L'Heureux
(Jewish General Hospital [JGH-01];
PC: Linda Robitaille)
Montreal, Quebec, Canada

Heather's main gift is one of

motivation and encouragement. "She is extremely positive about the study and will promote it whenever she can," said her recommending coordinator, Karen Truter. "She is a lively and vivacious person, always bringing laughter and joy to any of our meetings." A board member of the Huntington County Hospital in Quebec for the past ten years, Heather was referred to the study by her family doctor. Her mother and aunt both died from breast cancer, and she knew immediately that STAR was something from which she could benefit. Heather, who speaks both French and English, has always been a "patient representative," speaking out for those who cannot speak for themselves. "She is innovative and will bring new and fresh ideas to the committee," says Truter.



Marsha M. Minervini
(Munson Medical Center [GRR-01];
PC: Pam Bergman)
Traverse City, Michigan

As a survivor of cervical cancer, Marsha knows the devastation a cancer diagnosis brings to a patient and her family. Her younger sister is currently being treated for breast cancer, and she herself has had three breast biopsies, so she is very motivated to do anything she can to fight cancer. Marsha, a former commercial and residential contractor, now works full time as a realtor. She was honored by her peers by being awarded the 1998 Humanitarian/Community Service Award, the 2000 President's Award for her community and realtor involvement, and the 2000 Women's Council of Realtors Member of the Year Award. She is an avid spokesperson for STAR and has conducted two TV interviews for her site. Marsha's STAR coordinator, Pam Bergman, says that Marsha "displays excellent rapport" and is "articulate and well spoken." Marsha's favorite hobby is singing and she is very active with Sweet Adelines International and her church choirs.

Summer – 2001 Constellation Page-4



Susan R. Shea, Ph.D.
(Central Illinois CCOP [CIL-02];
PC: Peggy Verrill)
Springfield, Illinois

Susan is the director of the Instruction/Professional Development Department at the Illinois Education Association and has a doctorate degree in Public Administration and Higher Education. Her mother was diagnosed with breast cancer at age 50, and her sister was diagnosed with breast cancer at age 30. Susan chose to participate in STAR even though her mother and sister did not agree with her decision whole-heartedly. Her sister has since died from breast cancer. As a professional educator, Susan believes that the only way we can gain reliable information about treatment and prevention is through well-planned, unbiased studies. "She is an enthusiastic, articulate advocate of the breast cancer prevention studies, and she has been a ready volunteer for local media interviews. She is an interesting lady who will be an asset the PAB," says Susan's recommending STAR coordinator, Sid Shonkwiler.

"I am so pleased to be participating in the search for answers, [and] more options for women."

—Jackie Thomas,
STAR PAB member



Arlene E. Stevens
(Baltimore-Washington Regional
STAR Center [BWR-01];
PC: Joyce Holley)
Silver Spring, Maryland

"Arlene is enthusiastic about participating on the PAB and being an advocate for recruiting racially and ethnically diverse women to STAR," says her STAR coordinator, Joyce Holley.

Her mother had a mastectomy at the age of 24. Her father believed he saved her mother's life by agreeing to the surgery. He wanted her alive and did not care if her body was no longer perfect. Her brother had prostate surgery a few years ago and has been cancer free since.

Arlene, a native New Yorker, lived on St. Croix in the Virgin Islands for 23 years, where she knew many cancer victims and lost many friends. Her son and daughter grew up and married on St. Croix, and she became a grandmother there. When they all left the island to pursue their careers on the mainland, she followed. Although she has a background in marketing and public relations, she now enjoys managing the Washington office of a large Chicago intellectual property law firm.

Arlene has atypical hyperplasia of the breast, which motivates her to make a special effort to keep informed about health and breast cancer issues. Before joining STAR, she was reluctant to give up her hormonal therapy, but then, she says, "that became secondary to being involved, doing something that just might ensure my

daughter, daughter-in-law and two granddaughters a future free of breast cancer."



Jackie Thomas
(Fred Hutchinson Cancer Research
Center [PUG-01];
PC: Joelle Machia)
Issaquah, Washington

Hello! My name is Jackie Thomas. I'm a citizen activist in my suburban hometown of Issaquah, Washington. Husband Hank and I care deeply about the quality of life in our community. Hank and I met in Naples, Italy — I, a backpacking peacenik, and he, a U.S. Naval Officer. Our life together has included travel adventures and living in many parts of the U.S.A. Now retired in the Northwest, our claim-to-fame is nine grandchildren (teens to tots).

My mother and her sister both had breast cancer. I began yearly mammograms at age 35. At 37, I had my first cancer scare. I felt so powerless and ignorant, I vowed to learn all I could about breast cancer. I was lucky then, but wanted to be prepared for "next time." I was actively looking for an opportunity to be involved in the fight against breast cancer when the first Breast Cancer Prevention Trial came along. I supported that trial in every way I could. It was a tremendously positive and empowering experience. Now eligible for the STAR trial, I am so pleased to be participating in the search for answers, more options for women. I am honored and grateful for the opportunity to participate on the national Participant Advisory Board.



Hsiao-Mei Wiedmeyer
(Ellis Fischel Cancer Center
[ELF-01]; PC: Pamela Lucas)
Columbia, Missouri

"[Hsiao-Mei] is forever smiling and just makes you feel happy when speaking with her," says her STAR coordinator, Pamela Lucas. Hsiao-Mei, whose mother is a breast cancer survivor, is a child health project director in the Endocrinology Department at the University of Missouri. With her vast knowledge in clinical trials and bubbly personality, she has the ability to portray STAR positively to those around her. "I feel she is an excellent choice for the PAB, not only to increase her involvement in something that is very close to her heart, but also to serve as an advocate for the Asian/American community," Lucas says. ☆

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