

Frankly Speaking About Cancer: A Model of Patient Education

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ABSTRACT

Since 2001, the Cancer Support Community (CSC), formerly The Wellness Community, has developed, administered, and maintained the Frankly Speaking About Cancer (FSAC) series, an educational program providing an in-depth look into several concerns faced by cancer patients and loved ones. FSAC combines educational booklets, professionally-led workshops held across the country, and tailored web-content available on the CSC website. Topics span a variety of tumor types and commonly-faced issues across tumor types. CSC is dedicated to developing programs of excellence that empower those affected by cancer to become Patient Active partners with their health care team. FSAC materials, guided by Social Cognitive Theory, are frequently updated with the most current medical information. Free workshops address unique needs often unmet elsewhere, are widely attended nationwide, and are successful at meeting program goals.

Program Background

CANCER SUPPORT COMMUNITY

The Cancer Support Community [uniting The Wellness Community and Gilda's Club Worldwide] is a non-profit organization that provides free emotional support and education for cancer patients and their loved ones.

PATIENT ACTIVE CONCEPT

People with cancer who actively participate in their care along with their healthcare team will improve the quality of their lives and may enhance the possibility of recovery.

ABOUT THE FSAC PROGRAM

Launched in 2001 with the support of funding from pharmaceutical companies, the FSAC program sought to provide in-depth coverage of topics of relevance to those affected by cancer, guided by the Patient Active concept, that are often not otherwise available in a comprehensive format. Program topics are both cancer-specific (e.g. advanced breast cancer) and of interest to a broad audience (e.g. coping with the cost of care). Program materials represent the most up-to-date content and are updated to reflect new advances in knowledge, and include:

- Web-based materials
- Booklets
- Professionally-led workshops held across the country
- Online radio series and Podcasts

Those affected by cancer typically account for up to 70% of workshop participants, with the second largest group of attendees being family members and spouses.

EVERY FSAC PROGRAM:

- Provides sound clinical information in easy-to-understand terms.
- Clarifies scientific advances for specified cancer diagnosis and treatment.
- Provides tools to improve communication for trusting and productive relationships among cancer patients, family members and medical professionals.
- Provides tools that enable patients to better manage emotional and physical side effects of cancer for a better quality of life.
- Empowers people affected by cancer to ask and discuss important and personal questions with their health care team, and loved ones.
- Engages and creates a supportive community of survivors – where people affected by cancer can share thoughts and feelings to better cope with the challenges, successes, and life lessons that cancer brings.

PROGRAM OUTREACH

The FSAC program is ongoing, though the numbers below are accurate through 2009:

- Over 780 workshops nationwide
- Over 2,600 workshop attendees
- Over one million people have sought tailored information from the website
- Over 350,000 kits and educational booklets distributed
- Podcasts, media coverage, partners, etc
- 60,000 online radio listeners



"I liked the personal group setting. The facilitator did a good job of making everyone feel comfortable about talking."

–TWC Workshop Participant, FSAC Coping with the Cost of Care

"The booklet is exceptional!"

–TWC Workshop Participant, FSAC Coping with the Cost of Care

"This workshop was comforting and made me feel better about myself and my treatment."

–CSC Workshop Participant, FSA Advanced Breast Cancer

Current and Past FSAC Programs

Frankly Speaking About Advanced Breast Cancer

Frankly Speaking About Colorectal Cancer

FSAC: Lung Cancer

FSAC: Spotlight on Liver Cancer

Frankly Speaking About Cancer Treatment

FSAC: New Discoveries

FSAC: Coping with the Cost of Care

FSAC: Melanoma

Frankly Speaking About Lymphoma

Patient Active Guide to Living with Ovarian Cancer

Cancer Vaccines

Open to Options, Cancer Clinical Trials

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ABC: GlaxoSmithKline, AstraZeneca, and Abraxis; CRC: AZ, Roche; Cost: Genentech, Eli Lilly; Cancer Treatment: Amgen; Lung: GSK, AZ, Lilly; Lymphoma & Ovarian: GSK; Clinical Trials: GM and Genentech; Vaccines: Sanofi Aventis & EMD; New Discoveries: Genentech

Evaluation of Programs

- Formal evaluation of program workshops has been conducted on all workshops to date across programs (>70% response rate, averaged across topics)
- Evaluation results demonstrate the impact of the workshops and strongly support that the educational model is effective across all topics
- Workshop participants reported increased knowledge after attending the workshop (86-96%)
- Most participants (97%) endorsed the critical role of communicating openly and honestly with their medical team
- Nearly all participants (92-99%) stated that they would recommend the program to others

For more information

Please Visit:

www.cancersupportcommunity.org or

call 888-793-9355