

Lance Armstrong Foundation Survivorship Conference: Live Strong!

A motto of the Lance Armstrong Foundation is: unity is strength, knowledge is power and attitude is everything. Those themes resonated through the national convening of delegates to the LAF Live Strong Survivorship conference October 27 to 29 in Austin Texas. As one of the 800 delegates selected to participate in this conference, it was once again reinforced to me that cancer is an equal opportunity disease regardless of age, race or gender.

However, I am grateful to be a breast cancer survivor as we are a true critical mass represented by wonderful organizations such as FBCC, NBCC, Y-Me, etc. Such is not the case for many individuals who receive the sobering news: "You have cancer." For example, I sat next to a young woman with a six year old child who had gone through malignant melanoma and then a vaginal cancer diagnosis. She has not had the kind of resources and support that are available to those of us surviving breast cancer. Thus, in our health care crisis, we have been presented with a great opportunity, the ability to support each other and advocate for our breast cancer agendas on a state and national level.

I would like to take this opportunity to share some sobering facts with you about cancer which were covered in conference materials:

- * More than 10 million people are currently surviving cancer in the U.S.
- * 1.39 million persons will receive a cancer diagnosis this year (approximately 229,000 of whom will be diagnosed with breast cancer).
- * One in 3 women and 1 in 2 men will be diagnosed with cancer in their lifetime (1 out of every 7 women will be diagnosed with breast cancer).
- * Three out of 4 families will help care for a family member with cancer.

Hence it is virtually impossible to escape being touched by cancer. The Center for Disease Control has deemed that anyone in a close relationship to a person diagnosed with cancer such as family, friends or coworkers, is also a survivor. Consequently, it is imperative that there be a more aggressive approach to eliminating cancer as well as the development of resources to assist patients and their significant others who must cope with this disease.

Several motivational speakers, including Sen. John Kerry and Elizabeth Edwards (breast cancer survivor) spoke eloquently and emotionally of their own journey through cancer while continuing to participate in the political process. One speaker, Genne McDonald, created Team Survivor North Florida. This is a nonprofit organization for female cancer survivors allowing them to become physically active and participate in athletic events. Team Survivor members participate in everything from tai chi to dragon boating and compete in triathlons, 5ks, century rides and half marathons. FBCC members

in North Florida should consider contacting Genne who works as a physical therapist at the University of Florida Department of Physical Therapy. If you are interested in this program, you may contact me at vandenan@fiu.edu.

The overall goal of this conference was to empower delegates to return to their communities and assist in the development of more services to enhance cancer survivorship. An example of one educational session was when participants separated into small groups. All participants were given two questions to answer within their table discussions: what were the largest obstacles faced by you during your cancer experience and what would you change about your cancer experience?

The primary themes emerging from the answers included:

- 1) receiving poor or inadequate information regarding treatment options,
- 2) challenges in working with the healthcare team (i.e. "Dr. Ego"),
- 3) lack of clarity about side effects,
- 4) insurance/financial problems,
- 5) a lack of patient support resources,
- 6) deficits in supporting the cancer patients' family,
- 7) emotional and mental health issues, and
- 8) practical challenges (i.e. transportation to treatment, child care, etc.).

Themes that emerged from the "what would you change" question included:

- 1) improving accessibility to help from patient navigation services during and after treatment,
- 2) provision of support to caregivers,
- 3) improving communication with the healthcare team during and after treatment,
- 4) taking better care of oneself,
- 5) acquiring support, and
- 6) information about financial realities.

Outside of those two questions, each region was required to brainstorm solutions to two unmet needs. For the Southern region which included participants from Florida, Georgia, South Carolina and Tennessee our discussion areas were centered around creating a more flexible and responsive insurance system and better communication between

survivors and health care professionals during and after treatment.

Ideas that the Southern region came up with regarding insurance included:

- a) expanded coverage/reimbursement for clinical trials, new drugs, prevention/screening and elimination of pre-existing condition clauses,
- b) creation of a national office of insurance oversight and/or an insurance ombudsman,
- c) better coordination between MDs, patients and insurance companies, and
- d) advocacy to make insurance reform a national priority.

In terms of improving communication between patients and health care professionals during and after treatment, suggestions included:

- a) creating common information resources,
- b) ensuring that all patients receive copies of their medical records and care summaries,
- c) clearer definition of role of the healthcare team,
- d) training for health care professionals on how to communicate with patients, and
- e) teaching medical students about patients needs, cultural sensitivity and patient responsiveness.

Each participant was required by the end of the conference to come up with a goal that they were willing to implement as a Live Strong survivor. For my goal, I would like to establish a network of Florida cancer survivors within the community of women who partner with women. The purpose of this network would be to serve as a support and knowledge sharing network for women who are newly diagnosed as well as those who have completed treatment. This network can be an electronic community as well as having the potential to host regional or local gatherings. There is a real need for this kind of network since women who partner with women are presumed to be at three times greater risk for breast cancer based on barriers to care including prejudicial/ discriminatory treatment within the health care system, lifestyle choices plus less access to insurance and financial resources. Please contact me if you are interested in participating within this network or if you know someone who may be interested: vandenan@fiu.edu

In summary, the Lance Armstrong Foundation Live Strong conference was an educational experience. It appears to me that FBCC and NBCC could consider this foundation to be an ally in terms of goals related to advocacy, patient/survivor education and empowerment. For more information about LAF, visit their website: www.livestrong.org. Let us all Live Strong.

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