



The Voice of the Patient Transforms Care

By **Martie Carnie**, *Co-Chair of the Adult Patient and Family Council*
and **Janet Porter**, *Chief Operating Officer, Dana-Farber Cancer Institute*

Excellent patient care can only be delivered if care providers admit they do not know what is best for patients and families and if they commit to listening to their voice – every day, in everything they do. Slowly many organizations are realizing this. The Joint Commission wants to know how patients are involved in their own care; the Massachusetts legislature recently passed a law that every hospital in the state of Massachusetts must have a plan to establish a patient and family advisory council by September 2009.

Dana-Farber Cancer Institute and Brigham and Women’s Hospital recognized the need to involve patients in decision-making and established their **Adult Patient and Family Advisory Council (PFAC)** in 1998. Dana-Farber and Children’s Hospital established the pediatric version the following year. Today the Council members establish annual goals and then participate on committees – well over 100 to date – to weigh in on everything from selecting the latest Vice President to the video on participating in clinical trials to the annual patient safety measures and goals. We would not think of launching a patient care initiative without a PFAC member being right there to share their wisdom.

The PFAC regularly hosts visitors at their monthly Council meetings; the visitors want to observe and learn how they might take lessons back to their respective organizations. There is nothing like seeing the Council in action to understand how they shape cancer care here. With eleven years of experience, we can say that becoming patient and family-centered is a journey and that we have matured in our understanding but still are only in our adolescence in terms of learning how to listen well. But some lessons we have learned *Continued on page 2 >*

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“We would not think of launching a patient care initiative without a PFAC member being right there to share their wisdom.”

ACE Calendar

ACE 2010 ANNUAL MEETING

FEBRUARY 13–16
SAN DIEGO, CA
WESTIN HORTON PLAZA

ACE 2011 ANNUAL MEETING

JANUARY 26–29
NEW ORLEANS, LA
THE ROOSEVELT HOTEL

President’s Message

Patrick A. Grusenmeyer, ScD

Senior Vice President, Christiana Care Health System

Healthcare Reform and the Challenge of Providing Excellent Care



Healthcare reform is currently the hot topic, in the White House, on Capitol Hill, and at healthcare providers, insurers and pharmaceutical companies around the country. One of my favorite healthcare authors, Atul Gawande, a Boston physician (www.gawande.com) has written an article for the *New Yorker* magazine titled *The Cost Conundrum* (www.newyorker.com/reporting/2009/06/01/090601fa_fact_gawande). The article has gotten a lot of attention since President Obama brought it to a White House meeting and cited its findings as part of the need for healthcare reform (www.nytimes.com/2009/06/09/us/politics/09health.html?_r=1). In the article, based on the Dartmouth Atlas of Healthcare data, Gawande cites differential Medicare spending in different parts of the country. For example, Medicare spent \$16,351 per beneficiary per year in Miami, the highest

cost city in the country, almost twice the amount spent in San Francisco at \$8,331 per beneficiary. New York State had the highest state average at \$9,564, while Hawaii had the lowest per beneficiary annual cost at \$5,311. Gawande spends most of the article describing McAllen, Texas, the second highest cost city in the country and describes what he found there. The President and some members of Congress are highlighting this as an example of a broken system. The article is worth the read.

This article reminded me of another piece by Atul Gawande, published in the *New Yorker* in December 2004 titled “The Bell Curve” (www.newyorker.com/fact/content/7041206fa_fact). In this article, Gawande cites the story of a young girl diagnosed with cystic fibrosis and her parents’ journey to find excellent care for her. Gawande postulates that the quality of healthcare providers, physicians and hospitals, as groups, follows a bell shaped curve, with a small number of poor quality providers on the left hand tail of the

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THE VOICE OF THE PATIENT TRANSFORMS CARE

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might be helpful as you embark on your journey.

First, senior leadership needs to have a philosophy of being patient and family centered. This does not mean just that quality improvement staff occasionally talk to patients and families. The organization's leadership must be philosophically committed to actively engaging with patients and families and they must be excited about how this will transform the care process. At Dana-Farber, the Chief Medical Officer, Chief Nursing Officer and Chief Operating Officer – along with other key staff – attend every PFAC meeting. The CEO often tells stories about how the patients picked the architect for our new building because he made sure they were on the selection committee.

Second, start small. Recruit some patients and family members to sit on established committees to weigh in on plans. Do some orientation of those patient and family members to your organization and to issues like patient confidentiality. Dana-Farber had over 100 patient and family members participate in the first year alone. Bring the patient and family members together and have them identify what their goals might be for the first year. Then have them stay focused on those goals throughout the year.

Third, recognize the PFAC should self-govern. Have the PFAC draw up bylaws that spell out how they want to be organized and do business. The PFAC needs to recruit and select members and establish the expectations and parameters. In recruiting patient and family members it is important that they have a

compassionate midset, patience with the process and that they understand the true partnership with staff as well as an unbiased view of their experience. There is no room for personal agendas. PFAC members need a global perspective of the patient/family journey as this is vital to the culture shift.

Fourth, commit resources to helping organize and staff the process. Whether they are located within the volunteer department or quality improvement or another department, the organization has to recognize that this work requires staff to support the PFAC. At Dana-Farber, there is a staff liaison for PFAC and a full time administrative assistant. No PFAC members are ever paid – a policy that they fully support – even though some members are here as much as 30 hours a week.

Fifth, communicate the value of having patients and families involved by celebrating their role in a major decision. At Dana-Farber, many say the turning point was when the inpatient floor plan favored by patients was selected over the floor plan favored by staff.

Eleven years later, it is hard to imagine how hospitals run without a PFAC. Having a ready way to touch base with patients and make sure that we are doing it right makes delivering care so much easier. The challenge is that many administrators feel threatened or see this philosophical change as creating more work when in fact it is easier because you do things right the first time by listening to those who know first-hand what how care should be delivered. ■

“PFAC members need a global perspective of the patient/family journey as this is vital to the culture shift.”



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Ed. Note: Hematology & Oncology New & Issues (HONI) is featuring the ACE Board of Directors in a monthly "Industry Insiders" column, which we are pleased to reprint here.

HONI's "Industry Insiders" – Q&A with ACE Board

Submitted by **Elaine Kloos, RN, CNA-BC, MBA, ACE Board Member and Senior Consultant, Oncology Consulting Management Group**

Q: HONI: What traits define leadership in a physician owner and a practice administrator in community-based cancer centers, today?



Elaine Kloos
RN, CNA-BC, MBA
ACE Board Member

A: KLOOS: The most important traits for a leader in the field of oncology (or any field for that matter), whether physician owned or community based centers are:

1. **VISIONARY:** A true leader should possess vision and must actively and consistently share the vision with all stakeholders. One must be forward thinking and keep abreast of emerging trends and technology. Time must be put aside to strategize and plan for the future and not get bogged down in the constant day-to-day mundane issues.
2. Know your **STRENGTHS** and know how to surround yourself with competent team members that possess strengths that you do not. A leader must be competent in all aspects of oncology but not necessarily an expert in every area. Know when to ask for help and how to delegate.
3. **FOCUS ON AND BUILD RELATIONSHIPS** with honesty, integrity and empathy. A successful leader must develop and build a great team to carry out the work and share the vision.
4. **MENTOR FUTURE LEADERS:** Don't be afraid to select your future replacement and mentor that person to become a leader.
5. **PASSION, PASSION, PASSION:** Leaders must possess passion in everything they do. One must be able to inspire staff and colleagues to follow them and articulate the vision, dreams and plans with enthusiasm. A great leader must be motivating, energetic and optimistic. ■

"...time must be put aside to strategize and plan for the future..."

PRESIDENT'S MESSAGE

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curve, a high number of "average" providers in the tall bell of the curve, and another small number of truly excellent providers in the right hand tail of the curve. He cites the different outcomes and survival rates for different cystic fibrosis treatment programs, recognizing that the parents' search for excellent care improved their child's quality of life and likely increased her survival. The moral of the story was that those providers who worked tirelessly for excellence truly affected the outcomes for their patients.

I expect that if someone performed a similar analysis of cancer providers, they would find a similar bell shaped curve of quality, a small number of providers providing below average care, a large group of "average" providers and a small number of excellent providers, with significant differences in patient outcomes between the groups of providers. However, if you ask any cancer program physician or executive to name the most important aspect of their cancer program, to define what sets them apart from their competition, they will tell you that their program provides excellent care. The reality is that most programs provide average care. The bad news is that some provide below average care.

The challenge for patients and their families is to identify those programs that provide excellent, evidenced based care. As Gawande states, getting the kind of data to determine who the excellent providers are is a challenge for patients with any disease, especially for complex diseases such as cancer.

Quoting Gawande "The hardest question for anyone who takes responsibility for what he or she does is What if I turn out to be average?" If I'm below average, then the answer is easy – I should do something else. But what if I'm solidly average? Somehow, what troubles people isn't so much being average, as settling for it. The challenge is to move the entire bell curve to the right, to improve care for all.

The challenge for us as cancer program executives is to improve the quality of care provided to our patients so that we are providing excellent care, and not succumbing to providing good care.

2010 Annual Meeting

Planning is underway for the 2010 Annual Meeting to be held at the Westin Gaslamp Quarter in San Diego, California, February 13 – 16, 2010. Joy Soleiman, ACE President-Elect and the ACE Education committee, leads the planning efforts. If you would like to be part of the planning, please contact Joy at joy.soleiman@mail.jci.tju.edu. ■

A Collaborative Partnership with C-Change

By Brian E. McCagh, FACHE
ACE Representative to C-Change

“This unique assembly of cancer leaders from the public, private, and non-profit sectors has allowed for the effective development and implementation of five major initiatives.”

I am pleased to share this update on ACE’s 10 year collaborative relationship with **C-Change ... Collaborating to Conquer Cancer**. It seems hard to believe, but it was ten years ago after serving as ACE’s President that I was asked by the Board of Directors to represent our professional organization and its membership as a collaborating partner with a newly formed organization, the National Dialogue on Cancer. The founding members of this organization, President and Mrs. George H.W. Bush, wanted to make a significant impact on cancer in our country. They called upon their contacts in government, the non-profit and private sectors to establish this new organization whose mission is “to eliminate cancer as a major public health problem at the earliest possible time by leveraging the expertise and resources of its members”. **C-Change** is the only organization that assembles cancer leaders from the three sectors – private, public and not-for-profit – and from across the cancer continuum: research, prevention, early detection, treatment and quality of life.



The Association of Cancer Executives was invited to join this organization in 1999. As ACE’s representative, I was the 13th collaborating partner to join this organization that has focused on the “war on cancer.” **C-Change** was previously named the **National Dialogue on Cancer**.

The purpose of the **C-Change Annual Meeting** is to engage the membership in identifying common challenges and opportunities in cancer research, practice, and policy that can be effectively addressed through the multi-sector collaboration and to report on the progress and status of the organization. During the meeting, speakers and participants discuss near- and longer-term issues that define its strategic priorities each year. The main themes of the organization include: maintain a unique presence, addressing relevant issues, and leveraging the membership. Current **C-Change** initiatives consist of member-driven, collaborative efforts in the areas of research, access to quality cancer services, and support for cancer control efforts. This unique assembly of cancer leaders from the public, private, and non-profit sectors has allowed for the effective development and



Former President George Bush and former First Lady Barbara Bush are Co-chairs of C-Change and hosted the Annual Meeting in Kennebunkport, ME, in June.

implementation of five major initiatives between 2003 and 2007, including: prevention and early detection, research and clinical trials, access to care, advocacy, and capacity building.

C-Change has established criteria for initiative investments of financial and human resources. The major criteria for investments include:

- Hold significant potential to impact incidence, mortality, morbidity, survival and/or quality of life
- Depend upon access to the three sectors for development and dissemination
- Fill a consensus need/gap or accelerates effort significantly
- Address issues that are not likely to be addressed or resolved in a timely manner without C-Change leadership
- Hold broad resonance/appeal across membership
- Represent leadership consensus that project strategy and tactics are likely to achieve results

The most recent **C-Change Annual Meeting** was held in Kennebunkport, Maine on June 11th and 12th. President and Mrs. Bush hosted the meeting which provided the membership with an opportunity to discuss and plan our next collaborative steps in the context of a dynamic and challenging environment for cancer research, policy, and practice. Over 100 members attended this meeting. The meeting ended with President Bush’s 85th birthday parachute jump in Kennebunkport.

The **C-Change** Board of Directors has been chaired by LaSalle D. Leffall, Jr., MD, FACS. The organization is very effectively led by Tom Kean, PhD and his exceptional team of ten employees. ■

ACE Welcome New Members

Since May, 2009

■ **Vijayan Aroumougame**
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YOUR INPUT IS IMPORTANT TO US!

ACE appreciates member feedback and suggestions to better serve you. Please e-mail your questions or comments to info@cancerexecutives.org

Share Your News

Announce your organization's achievements, program changes, staff transitions and events to the entire ACE membership! Send an email with your news and press releases to: info@cancerexecutives

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ACE Committee Updates

Education

*Joy Soleiman, Committee Chair
Kimmel Cancer Center at Jefferson*

The ACE Education Committee is working hard to make our 16th Annual Meeting to be held February 13-16, 2010 in the beautiful Westin Gaslamp Quarter of San Diego, California a great success. Members of the committee are:

- Joy Soleiman (Chair), *Kimmel Cancer Center at Jefferson*
- Liz Arkin, *Alliance Oncology*
- Christopher Collins, *ECC Management Consultants*
- Eric Doescher, *UT MD Anderson Cancer Center*
- Linda Ferris, *Renown Institute for Cancer*
- Marsha Fountain, *The Oncology Group*
- Teri Guidi, *Oncology Management Consulting Group*
- Nancy Harris, *St. Joseph Hospital*
- Brian McCagh, *GBMC*
- John Robb, *FKP Solution Management*
- Jeanne Rogers, *Abramson Cancer Center*
- Kelley Simpson, *Oncology Solutions*
- John Surprenant, *Baycare Health*
- Cat Taylor, *South Nassau Community Hospital*

The committee has begun bi-weekly conference calls. I hope you have all completed the on-line member survey evaluation so we can design the conference sessions to meet your needs. We are looking forward to hearing from each of you. Cat Taylor and John Robb are working hard on the Oncology 101 pre-annual meeting program. They have been speaking with past attendees to find out which session work best and design a meeting that will be of great help to new oncology administrators. If you have any ideas you would like to share, please feel free to contact me directly at joy.soleiman@jefferson.edu.

Newsletter & Publication

*Colleen Jernigan, PhD, RN, AOCN, Committee Chair
UT MD Anderson Cancer Center*

This issue of *ACE Update* features the Dana Farber experience with PFAC and patient involvement in the decision making process. The article, which offers highlights and suggestions from a presentation during the last ACE Annual Meeting, is co-authored by Janet Porter, Chief Operating Officer and Martie Carnie, Co-Chair of the Adult Patient and Family Council.

We're also delighted to bring you an article on ACE's 10-year collaboration with C-Change, written by ACE's Representative to C-Change, Brian McCagh, FACHE.

As always, if you are interested in working with us this year or have an idea for an article please feel free to contact me at cjerniga@mdanderson.org.

Vendor Relations

*Matt Sherer, Committee Chair
John B. Amos Cancer Center*

The Vendor Relations Committee had our first conference call. We are working on slightly changing our sponsorship levels for our 2010 meeting and we are pleased to report that we have already had some sponsors recommit to sponsoring again! We should finalize the meeting's prospectus brochure in early July. At that time, we will ramp up with contacting potential sponsors and exhibitors for the 2010 meeting. If you know of any vendors that we should contact, please e-mail me (matt.sherer@crhs.net) or Brian Mandrier at bmandrier@cancerexecutives.org.

Did you miss the 2009 Annual Meeting? Get up-to-date with the Meeting Notebook! Want to know what was discussed at the Cancer Center Building Blocks Conference? Presentations are available in CD-ROM!



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16TH ACE
ANNUAL MEETING

SAN DIEGO
CALIFORNIA

FEBRUARY 13-16, 2010
WESTIN GASLAMP QUARTER

Save the Date