

## **One Patient Advocate’s Perspective on the 2008 Era of Hope Meeting**

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The Era of Hope Breast Cancer Meeting was held on June 25-28, 2008 in Baltimore, Maryland. Although advocates are having an increasing presence in similar scientific meetings (e.g., AACR, ASCO, SABCS), their presence could not be missed at this meeting. Patient Advocates represented approximately 15% of the 1,500+ attendees, co-chaired each session, and were included in each plenary session. Indeed, the Q&A sessions sometime felt dominated by advocates. I felt that this was a mixed blessing. Although I am a strong supporter of advocates being actively involved in all aspects of research, and am confident that our presence has had a positive impact, I believe involvement comes with a significant responsibility. I observed many violations of these responsibilities. As a consequence, I fear that many of the young scientists present will be reticent about engaging with advocates in the future. Some of the dos and don’ts that I believe are incumbent on advocates who attend scientific meetings follow.

<b>Advocate Participation in Scientific Meetings</b>	
<b>Do’s</b>	<b>Don’ts</b>
Focus on the science	Focus on your own cancer experience
View this as a scientific meeting	View this as an opportunity for a political advocacy
Ask informed questions during public Q&A and/or naïve questions in hallway conversation	Ask personal and/or naïve questions or make political points during public Q&A sessions
Monitor your (and other advocate) involvement	Monopolize discussion or be totally reticent
Attend and actively engage in most sessions	Take advantage of local shopping and entertainment opportunities during most sessions
Significantly engage with scientists	Spend the entire meeting with other advocates

In addition to the involvement of advocates, a unique aspect of the Era of Hope Meetings is their focuses on research funded by the Department of Defense (DOD) Breast Cancer Research Program (BCRP). In 1971 President Nixon declared a “War on Cancer” that was led by the NCI. Twenty years after this declaration, in part due to frustration with the lack of breakthroughs, advocates played a significant role in obtaining additional federal funding for Breast Cancer research. The incremental funding was to be managed by the DOD and new approaches to distributing funds were to be used. In particular, advocates were to play a key role in establishing program priorities and reviewing applications for funding. Further, research was to focus on innovation and impact, and award mechanisms were established to foster synergistic and collaborative science. How much progress has been made in the fifteen years since the DOD has been funding breast cancer research? Here I also came away somewhat ambivalent. We are clearly a long way from “Eradicating Breast Cancer” or even achieving Von Eschenbach’s (then head of NCI) challenge in 2001 “to eliminate suffering and death due to cancer.” But, of course we have made progress. Has the DOD funding made a difference? Probably, but it seems more incremental than revolutionary. By this I mean that with more dollars there would have almost surely have been more progress. Further, while there have been some systemic changes in research (e.g., more translational work, more big, synergistic and collaborative projects, and more advocate involvement), I suspect societal, demographic and technological changes are at least as responsible as the DOD funding and advocate involvement.

It is of note that among the most exciting scientific presentations to me and a number of advocates with whom I spoke, was by a scientist who had never received DOD funding. In particular, Thea Tlsty of the University of California at San Francisco presented a plenary talk titled “Abrogated Response to Cellular Stress Identifies DCIS Associated with Subsequent Tumor Events and Defines Basal-Like Breast Tumors.” This talk summarized more than ten years of basic and translational science that studied the pathways involved in progression from normal breast cells to hyperplasia to DCIS and eventually to invasive cancer. She and her team have identified specific biomarkers that can discriminate between DCIS that will become invasive or not. This seems to be very close to being ready to apply in the clinic where it would have a large impact on the 25% (and increasing) of patients whose initial diagnosis is DCIS.

I will briefly highlight four other presentations that I found especially innovative and inspiring and who were funded by DOD. You can find their abstracts in the proceedings which are available at: <http://cdmrp.army.mil/bcrp/era/eoh2008/proceedingsbook.pdf>.

1. Nimmi Ramanujam from Duke talked about: “Functional and Molecular Optical Diagnostics.” She is a bio-engineer who won an Era of Hope Scholar award. She seems to be doing some innovative work that is likely to soon lead to less invasive and expensive and more accurate and highly portable diagnostic tools based on the normal light spectrum.
2. Stephen Johnson from Arizona State University talked about: “Toward a Prophylactic Vaccine for Breast Cancer.” He is not a breast cancer researcher, but is the inventor of the gene gun and gene vaccines. His talk was about developing a prophylactic vaccine for breast cancer that could be given to all women once, and could significantly reduce their susceptibility to breast cancer. He believes he could have his vaccine in clinical trials within a few years and on the market within ten.
3. Lillie Shockney from John’s Hopkins talked about: “How to Help Your Patient with Metastatic Disease Make a Difference for the Next Generation.” She talked about how she (a nurse and breast cancer survivor) set up John’s Hopkins Breast Cancer Autopsy Program. On the one hand, this program has allowed breast cancer researchers to learn a great deal about the molecular relationship between primary cancers and metastases. On the other hand, the humanistic approach she used in setting up the program was extremely moving and a model to be applied to similar programs, as well as patient care more broadly.
4. Laura Esserman from University of California at San Francisco presented multiple talks and posters on her DOD Center of Excellence (COE): “[Blueprint for Regional Excellence in Breast Cancer Care](#)”. The focus of this COE is to improve breast cancer treatment by offering one-stop, multidisciplinary patient care. This is achieved using information technology to provide information, evaluate risks, and identify trade-offs to help patients make informed choices. In addition to talking about the model and services, she presented a number of the computer-based decision tools.