

AACR 101st **ANNUAL MEETING** 2010
April 17-21, 2010 • Walter E. Washington Convention Center • Washington, DC

Rock Stars in Lab-Coats

a View of the 12th Annual Scientist↔Survivor Program at AACR-2010

by: Michael B. Lawing – Survivor Advocate



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To the Reader:

It is indeed an honor to present this document about an event that has been of profound value for me as I serve others through Survivor Advocacy.

As a member of the North Carolina Comprehensive Cancer Program, the Patient Advisory Work Group of Novartis Oncology, a volunteer with the Kidney Cancer Association and also with Hospice of Rutherford County, NC, USA, I have many opportunities to interact with Cancer Survivors and Caregivers as well as professionals at several levels in the Health Care Industry.

In this overview of the SSP, I have reflected on the many things that I was exposed to at the 101st Annual Meeting. My most prominent reflections have not been with the technical or clinical information that I received, but of the people that I had an opportunity to become acquainted with, to hear them speak, or to watch their enthusiasm permeate their entire countenance and body as they shared their passions in Cancer Research.

As I continue to be involved in Survivor Advocacy, my knowledge and understanding of the process of Discovery Research will of necessity broaden in order to be an even better channel of information for those with whom I interact: I look forward to becoming more fluent in the language of research.

For what it is worth, I dedicate this Summary View to all the researchers and Survivor Advocates who are striving to alter the course of human events through eliminating cancer. Although I mentioned several experiences and interactions that I had during the Annual Meeting, there were others that were equally as significant and inspiring.

While I do not feel I have made any medical recommendations in this view, any comments that could be construed in that manner should be disregarded and a competent medical person consulted.

Please overlook any grammatical blunders –I openly admit in the View that I don't have a clue on some things, please allow that statement to be broadened to include my writing and grammar.

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Please enjoy this view:
Warmest Wishes – Best of Success
Michael B. Lawing – Forest City, NC

ROCK STARS IN LAB COATS – *The Annual Meeting at AACR*



I knew that it would be a large event. It had to be. Any organization that has been in existence for over a century that was having an Annual Meeting where they have the run of the entire Walter E. Washington Convention Center in Washington, DC for five days has to be large. With a ballroom that has a seating capacity of over 4500 in an auditorium setting – *the* room in which the 2010 Nuclear Security Summit was held only days earlier – the Convention Center has over 2 million square feet of floor space in which to pack exhibits, poster displays, meetings, and a crowd of 17,000 people.

I had been accepted into the Scientist \leftrightarrow Survivor Program (SSP) as a cancer survivor. Along with my letter of acceptance was a link to a list of “assigned” reading materials with the suggestion that coverage of the materials would greatly enhance my ability to have a meaningful experience at the convention. A “tip sheet” hinted at the largeness of the event: Speaker and Mentor Bios gave clues that the “Scientists” involved in the program were very knowledgeable and capable people; and a list of the Survivor Advocates with their Bios revealed that I was in a group of thirty-six survivors from all over the US and several overseas countries, all of which were very engaged in some form of cancer-related activity.

In spite of my tremendously busy schedule I made time to “review” the assigned reading material; poring over facts, figures and details in preparation to be in a program where I would have an opportunity to “interact” with mentors from a scientific research-in-cancer background. While I was excited and honored to be participating in this program, I had very little information about it other than the lines from the AACR invitation that read: “*exposes advocates to special lay-language lectures, small group discussions and other interactions that provide a solid background in cancer research*” and a brief “*worthwhile undertaking*” from someone who had written a letter of endorsement for my enrollment into the program.

Large event? Yes... Worthwhile Undertaking? Definitely... Both were understatements. The 101st Annual Meeting of the American Association for Cancer Research with the theme: *Conquering Cancer Through Discovery Research* was about to begin... Turns out I didn’t have a clue as to what was about to happen.

On day one, the SSP’s initial meeting was scheduled for noon. Early registration and advocate poster set-up was at the Convention Center, a few blocks from the hotel where I was staying, then back to the hotel for lunch and the Opening Session. The distance of a few block’s stroll in Downtown Washington in April would have been a pleasure except for one thing: hand-foot syndrome (for me, very sore feet) – a side effect of the cancer medication that I had been taking for three years. For a 12-year cancer survivor with a strong resolve to make the best of things in spite of... side effects had become a normal part of life. My plan – save the walking (and the feet) for the huge convention center: take one of the million (or so it seemed) taxis in Washington.

The convention center isn’t large, it is *huge* – the downtown area of my hometown (Pop. 7500± would probably fit inside with room left over. In the center tons of people were sitting on every flat surface, including the floor, while hundreds of others were milling about the gigantic structure. There were people busy with their laptops, many people had backpacks with tubes poking out of them, and bits of conversation were overheard that dealt with medical sounding topics and phrases as excited people debated and exchanged ideas on all types of cancer research.

I noticed many people intently looking at a book twice the size of my local telephone directory (which I soon discovered was the program for the 101st Annual Meeting of the AACR.)



In the Advocate Poster room, I met Jeff, another advocate – I recognized him from his photo in the Bios; Jeff and I struck up a conversation and as we returned to the Grand Hyatt where the Advocates were quartered, he began to give me a brief, but excellent overview of the Scientist ↔ Survivor Program – this was Jeff’s third time in the program; his shared information was very helpful, and throughout the rest of the meeting, I received a lot of assistance from Jeff. Although Jeff had given me a better hint of what was about to unfold, still, in reality – I didn’t have a clue.

As we sat down to lunch in the opening session, Jeff introduced me to several people in a room that was obviously filled with talent. I began to realize that this was not only going to be a meeting with a lot of scientific knowledge passed around, it was going to be geared so that “ordinary people” could understand what was being presented. It was going to be the “worthwhile undertaking” I had been promised; it would also be one of the most intensive five-day “cram sessions” that I had ever experienced.

Jeff told me a little about the person that would be making the opening remarks in a few minutes; his description was filled with superlatives and accomplishments. As I thumbed through the Survivor Advocate materials that I had received an hour or so earlier, I saw that his glowing description only touched briefly on her listing of accomplishments.

As Dr. Anna Barker spoke to the group, I discovered something else – something that the Bio and that Jeff’s assessment of her failed to note – had this person been appearing before us with a musical group, with a rock band of some sort – she would be a Rock Star!

I had literally stumbled into a convention center where audiences would be assembling to listen and to be influenced by artists of a different sort who were skilled in the field of medical art; I would be participating in an experience where people with great talent would give of themselves to those who would listen; and to those who would move to the rhythm. It was a rhythm arising from test tubes clinking together; the music of machines humming as they scan tumors and peer into cellular structures; the excited musical tones of a research person as a breakthrough is discovered, or later; as the process is perfected, the elated songs of thanks of a mother who has witnessed her child cured of a cancer that would have ended in death a few years earlier.

I had stumbled upon a gathering of people with dreams of finding cures; of developing treatments and preventions from ugly, terrible, life-robbing maladies that have been lumped together into one word – cancer. I had stumbled upon a gathering of people who were skilled in many different instruments, used to playing in different orchestrations, many of them making music in their chosen field—Discovery Research – all of them determined to be the best that they could be in service to humanity.

I had stumbled upon a gathering of Rock Stars: Rock Stars in the field of Cancer Research – Rock Stars in Lab Coats as it were – and for some of them, for the next few days they would be sharing their talents, their knowledge, their passion, their vision and drive with us. Not only that, they would be listening and learning from us – Rock Stars in Lab Coats listening to their audience of Survivor Advocates.

Dr. Barker, in her opening remarks said something simple, direct, and very encouraging, “I think we are beginning to get our arms around the complexity [of cancer] and soon will be coming up with drugs that cure [certain types] completely...” I liked the words to that song – I became one of her fans. What I didn’t know at the time was that she had given a similar concert some three weeks earlier to a very different audience. At a US House of Representatives Subcommittee meeting Dr. Barker, the Deputy Director of the National Cancer Institute, stated:

We are dedicated to achieving a future where the shadow of cancer is removed from our lives and those of our children and grandchildren. This increasingly seems like an achievable future - as thousands of dedicated intramural and extramural scientists work tirelessly to make personalized cancer medicine a reality for every American. (Barker, 2010)



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“We are dedicated to achieving a future where the shadow of cancer is removed from our lives and those of our children and Grandchildren”

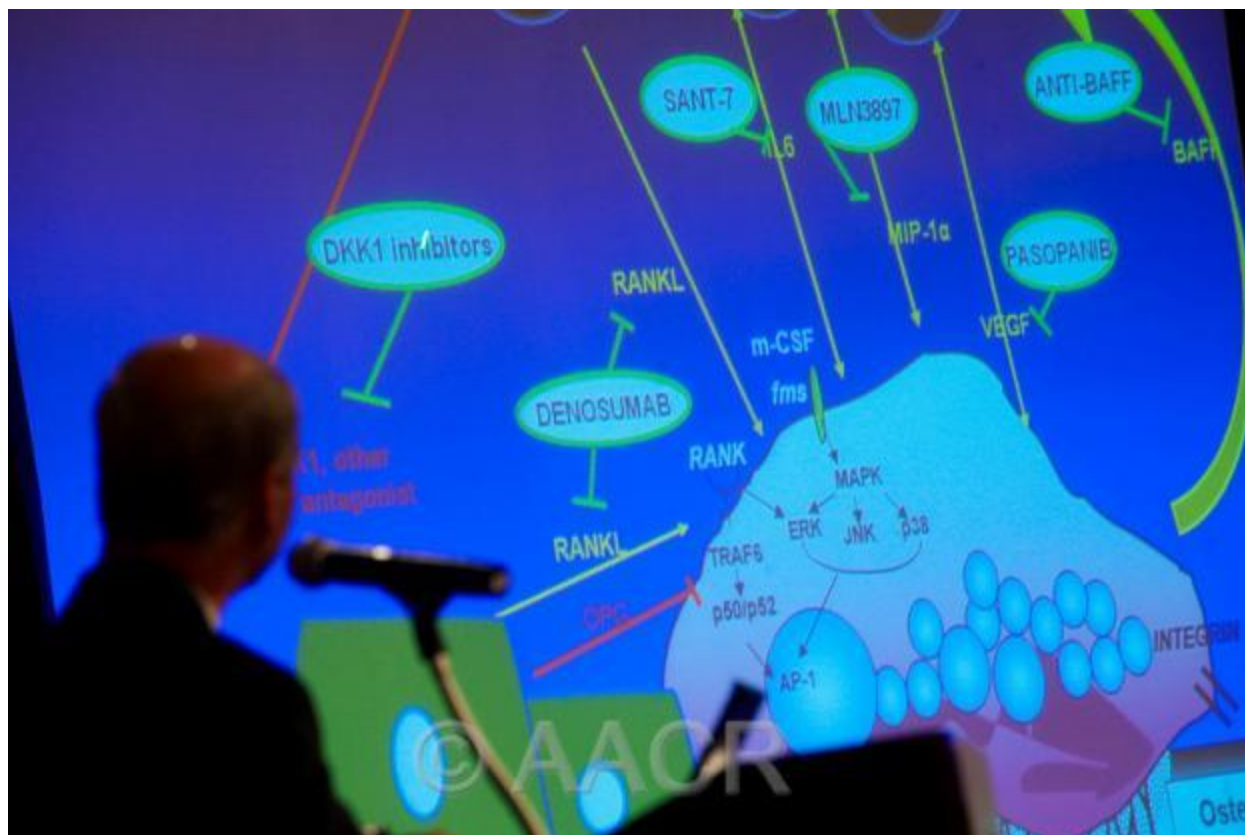
ANNA D. BARKER, PhD

Testimony before U.S. House of Representatives Subcommittee

I also didn't know at the time that entering her name on *Google* or *Yahoo* would yield page after page of results on projects that she and countless other Lab Coat Rock Stars were involved in; Projects aimed at removing the shadow of cancer, or as the theme of the Annual Meeting boldly proclaimed – *Conquering Cancer Through Discovery Research*.

When the opening remarks of Dr. Barker were concluded she wound her way around the tables in the room, making a point to chat with each Advocate. There were some who had been in the program before whom she welcomed in a way that she would greet an old acquaintance. As she and I spoke for a few moments, she quickly inquired of my cancer type, survival status, and advocacy involvements (somehow I felt that she already knew the details of every advocate in the room and was merely refreshing her memory). She then began to talk about the research that was underway at NCI on finding reliable biomarkers for twenty different types of cancer; one of which was Kidney Cancer – the type I had been diagnosed with in 1997. She once again expressed her optimism that the medical community was truly beginning to understand some of the complexities of cancer; she promised that during these meetings the group would have an opportunity to hear of dramatic changes that were taking place.

Her promise was wonderfully fulfilled. Not only did we have an opportunity to hear of changes, but because of the design of the Scientist Survivor Program, we would actually understand lot of what was said.



In the previous eleven years of the SSP, at the conclusion of the five day program, the moderator walked around the room with a microphone and allowed individuals to make comments about what they had learned or to make other statements. This year, the program would have six Working Groups, each of which would have a different topic to put together and

present at the SSP Closing Session and Celebration. We played musical chairs as we moved into our groups – the topic of my group was: *The Current State of Biomarkers in Cancer Research and Patient Care: Progress to Date and Future Directions*. I reflected back to the earlier comments made by Dr. Barker to me about NCI’s work on biomarkers and the fact that Kidney Cancer was one of those being targeted. Perhaps I didn’t have a real clue about what was going to take place in the coming days, but I knew that it was not a coincidence that I was in the Biomarker Working Group.

While all the Survivor Advocates and Scientist-Mentors would work closely with each other; getting acquainted, sharing insights and information, each Working Group would be drawn even closer together as they gathered material for summarizing and putting together a ten-minute presentation for the Closing Ceremony of the SSP. In this crowd of Survivor Advocates from all over the world (with a sprinkling of Rock Stars thrown in for good measure) someone who could barely read the music, let alone play an instrument in the field of medical research was going to have the opportunity to stand up and deliver Group Three’s presentation on biomarkers... I had been selected as the presenter for our group.

As a cancer survivor, I had long ago learned the value of a good support system. A support system is a tremendous asset if it is aware of the seriousness of the situation but strives to understand, encourage, motivate, help; and often – to simply tolerate the patient. As the rollercoaster ride of a survivor’s journey unfolds a good support system gently lifts up someone who has “bottomed out,” praises them for accomplishments, and many times remains silent – allowing just the knowledge of their care and presence to add strength and resolve for the survivor’s journey.

Each Working Group had excellent “support systems.” Mentors who were well acquainted with the complexities not only of cancer, but who were also familiar with the complexities of the Annual Meetings of the AACR were a great help to all the Advocates. Not only were they helpful in selecting “can’t miss” things to see or to attend according to the interests or needs of the individual, they would listen patiently to the day-to-day situations that many of the Survivor Advocates faced in their lives “back home.”

I especially appreciated two of the mentors assigned to our group that worked extra hard with me in preparation for the group’s presentation. Their efforts and insights were tremendous as they provided timely information and ever-present smiles of encouragement as we tackled understanding some aspects of the rapidly-changing world of cancer research and the quest for useable biomarkers.

Our Scientific Faculty Mentor, Dr. Aime T. Franco was a researcher from Memorial Sloan-Kettering Cancer Center, a cancer survivor, and was “actively involved with programs to advance early career scientists.” (AACR, 2010) Her dedication to cancer research and the furthering of the early careers of others was very evident as she described the process in very understandable terms. I learned quite a lot from this rising “Rock Star.”

Peggy J. Devine, founder and president of the Cancer Information and Support Network worked for decades as a lab scientist and research microbiologist before turning in her Lab Coat after her diagnosis of cancer to work in cancer advocacy. (AACR, 2010) As an Advocate Mentor, Peggy exuded that quality of experience, knowledge and confidence that assisted all in her Working Group to get more meaning and understanding from the SSP. She was a major source of encouragement and provided much valuable information from the standpoint of a Cancer Patient / Advocate.

As I went back to the hotel room after the opening session, I wasn't sure if I had a clue or not. But I did know one thing – I had an assignment.

Searching for Clues

When I was first diagnosed with Kidney Cancer in the fall of 1997, I knew very little about cancer, and absolutely nothing about Kidney Cancer. In short, I was literally clueless. Over the past dozen years of active survival, I have asked a lot of questions, and gotten a lot of good answers. There have also been many less-than-good answers given as well. Gradually, I began to learn things about Kidney Cancer from my medical team in whom I have a very deep trust. (It is a good thing to have a lot of trust in the people that you are entrusting your life to for treatment.)

In spite of the high degree of confidence in my medical team, there are still a number of unknowns that they freely admit exist in the treatment of kidney cancer; and with some cancers there are even more unknowns. While a lot of new treatment options (6) have been approved for Kidney Cancer in the past five years, there are no clear-cut biomarkers (or clues) that aid in determining which treatment is best for an individual patient that have been identified. Even though the death rate from Kidney Cancer has dropped from 13,000+ in 2005 to 8277 in 2009, much time and quality of life is often sacrificed because of lack of biomarker indicators for best treatment protocols. (Motzer, 2010 Annual Meeting) Through my involvement with the Member Forum of the Kidney Cancer Association, choice of treatment is a frequent situation that patients, caregivers, and the medical community are faced with. Some survivors will not respond well to the normal “first line” medicine, but the next medication or the next will be somewhat effective. For some, nothing works. A lasting, durable response is very unusual. As patients and caregivers experience several of these setbacks, it is not uncommon to hear them lament, “*Somebody needs to do something.*” Although I knew that a lot was “being done” I knew that the Scientist – Survivor Program could give me a lot of insight on some of the “specifics.” Not only did I have an assignment, as I became familiar with the scheduling, layout and concept of the Meeting, it was time to be on the alert for clues and answers that would be beneficial to me as a Survivor Advocate.

Day 2 began in the same way that Day 1 had ended. The SSP members were seated around tables – talking, getting acquainted, and sharing a meal. The Survivor Advocate Dinner at the Grand Hyatt the evening of Day 1 had been a time of Scientists and Advocates relaxing and getting to meet many new friends – this would continue throughout the meeting. We had an “all purpose room” where we ate, studied, relaxed and talked, and a “lecture room” next to it where special presentations were given for the Survivor Advocates. In addition, we were free to attend the scores of meetings, poster sessions and exhibits throughout the Convention Center. We were “part of the crowd” as well as receiving the special “lay-language lectures.” That could be compared to attending an Italian Opera or going to hear Springsteen and the E-Street Band.

It was time to move to the “Lecture Room” for our first Special Interest Session of the 12th Annual Scientist←→Survivor Program – the concert was about to begin.



DONALD S. COFFEY, PH.D.

Johns Hopkins University
School of Medicine

*"The Yoda of the prostate
cancer research world" –*

According to:
the Association for the Cure
of Cancer of the Prostate

Yoda

He strolled into the "Lecture Room" for the SSP with one of those disarming smiles that seemed larger than life. The room was filling up for the first formal Special Interest Session lecture of this year's program. Elsewhere in the convention center people were already packed in Exhibit Hall D for the Opening Ceremony where every seat was filled and hundreds more stood or

sat on the floor, but this room would allow for a face-to face, up-close and personal, question and answer setting.

The Daily Agenda listed the lecture topic simply:

What is Cancer? Donald S. Coffey, PhD, Johns Hopkins University School of Medicine.

Don Coffey placed his well-worn leather valise in an empty chair in front of my second row seat, nodded to those in the room, sat down, turned around and introduced himself and we began to talk. This was not the typical Doctor-to-person type conversation; not a conversation between two people who had just met – this was a conversation more like that of two friends that had not seen each

other in awhile; catching up on latest events sprinkled with reminiscing.

His bio in the Survivor Advocate notebook listed many of his accomplishments. He was a bona fide Rock Star in a Lab Coat – later I would find that he was dubbed the "Yoda [of Star Wars Fame] of the prostate cancer research world" by the Association for the Cure of Cancer of the Prostate (CaP CURE). (University of Louisville/Research Louisville, 2010) Doctor Coffey's lecture was indeed Yoda-like; a blending of pearls of wisdom, information, and facts about a difficult subject in an easy to understand personable manner. Listening to him was very similar to listening to a favorite uncle tell some of his fascinating stories. Coffey's "non-standard" approach to education [and lectures] includes the use of Rolling Stones recordings, Slinkys™ and wind-up toys to illustrate scientific points. (University of Louisville/Research Louisville, 2010)

This "Yoda" maintained that the most important tools in today's modern laboratories are still the minds and eyes of the researchers; that less than 10% of cancers are "inherited"- that most develop after a person is born; and that through the interactions of researchers and patients (like the Scientist-Survivor Program) a change of urgency on what researchers are focusing on and are doing has come about. His experience with prostate cancer (CaP) at a global level allowed him to observe that while every mammal has a prostate; only humans have an issue with prostate cancer. In China he cited that there were very few incidents of CaP among men in rural areas, but as these people migrated to larger cities and changed their dietary habits that this cancer began to become more common. One of the culprits in this case was how meat was being cooked, that charred meat increases the occurrence risks for prostate cancer.

Too soon the lecture ended – as we stood and left the lecture room, I could almost hear Don Coffey bidding us farewell with a phrase that has become so familiar:

May the Force be with You.



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We are not looking for new tools to do “better” science, but new perspectives and approaches to do paradigm-shifting science that will lead to exponential progress against cancer.

JERRY S. H. LEE, PH.D.
Lecture to Survivor Advocates
AACR -2010

CHANGING THE WAY WE LOOK AT CANCER

With a 50 lb bag of rice?

While the theme of this year’s Annual Meeting was *Conquering Cancer Through Discovery Research* – one of the underlying themes was a fundamental shift in the way that the research process is being done. The term “paradigm shift” had already been used frequently in the SSP in describing the initiatives put forth by the NCI:

The National Cancer Institute (NCI) is exploring new and innovative scientific approaches to better understand and control cancer. The Physical Sciences in Oncology initiative will establish scientific teams and individual scientists from the fields of physics, mathematics, chemistry, and engineering to examine cancer using approaches that have not been followed in cancer research to date.

(Physical Sciences in Oncology - Executive Summary, 2010)

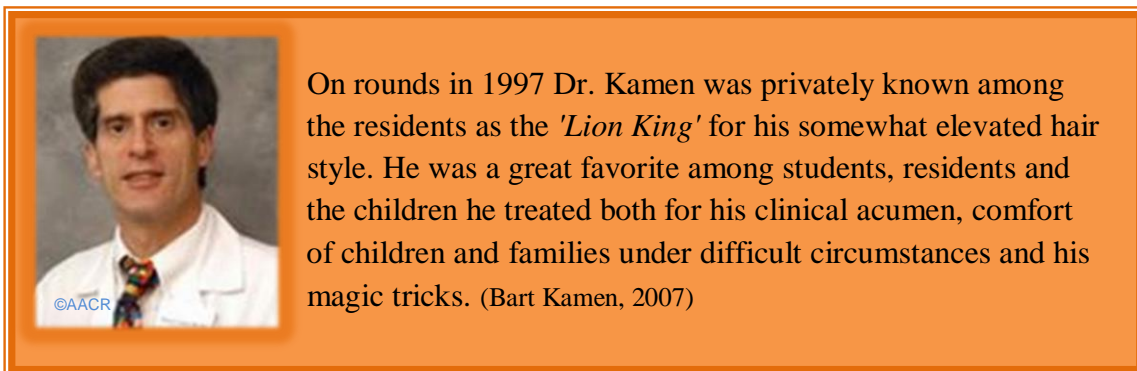
As Jerry S. H. Lee, PhD, of the National Cancer Institute outlined the *Physical Sciences in Oncology initiative* in his presentation, he also spoke of the difficulties that a cancerous cell has in causing the process of metastasis to come about. The body provides great resistance against the movement of cancer cells throughout the body. Shear forces and other forces deter and destroy many cells that find their way to the bloodstream. In nine years of living with metastatic cancer, I had never seriously considered how difficult it was for cancer cells to enter the circulatory system and then to emerge from it with the ability to form a metastatic tumor. I also became aware that the onset of metastases changes the way a case is handled; that there is a difference in a lot of the characteristics of the cancer in a new location. With the involvement of the Physical Sciences in cancer research along with the “Rat Doctors” as (Dr. Coffey loved to call them) new facets of the complexity of cancer are beginning to be found and understood. When asked what kind of force it took for a cancerous cell to enter or exit the circulatory system, Dr. Lee responded that it would be equivalent to stopping a 50 lb. bag of rice dropped from six feet with one hand held out at arm’s length!

Many other Special Interest Sessions would be held in the Lecture Room during this SSP. The primary difference in the lectures for the SSP and the ones that were being conducted throughout the rest of the Convention center was not the quality of content or the competency of the lecturer; it was the usage of lay-language terms and the opportunity to ask questions and to make comments. In our lectures we were listening to facts about the occurrence of resistance in EGFR (epidermal growth factor receptors) and the fact that 61 different genes have been isolated that can contribute to that resistance. One of the Advocates in the lecture had a question, but they also had a problem: they commented that they didn’t know enough to know how to ask the question. At this point, the lecture stopped, and efforts were made by the lecturer to figure out what needed to be asked. Like the leader of the band that stops the session to help one of the groups find the correct rhythm at a certain point, the Rock Star in a Lab Coat took the time to

find clues to determine the question. Once the question was identified, was asked, and was answered – the lecture continued. Each SSP presentation in the lecture room provided beneficial clues and information which would be useful for survivor advocates in their cancer journey or in working with another survivor or caregiver. But Rock Stars and clues were in many other locations as well.

“I don’t treat cancer – I treat people” was the first comment that I heard from Barton A. Kamen M.D.,PhD., one of the Facility Mentors of the SSP. With a profound interest in children’s cancer, a member of the Pancreatic Cancer Dream Team of researchers from Stand Up 2 Cancer, (Cutting Off the Fuel Supply, 2010) the list of his involvements and accomplishments could fill many pages. I had an opportunity to listen and to learn from Dr. Kamen on several occasions as he remained accessible throughout the Meeting for the Survivor Advocates to discuss, question and converse about all sorts of topics. He boldly declared that “killing” cancer cells were not the problem – the problem was how to kill the cancer cells and to keep the patient alive! After a few conversations with Bart, I decided that if I knew of a child that had cancer, I would want someone very similar to him treating that child. In describing his bedside manner, he revealed simple approaches to gaining the confidence and winning the cooperation of children and their parents that were undergoing diagnosis and treatment. Even with a busy schedule; with perhaps two or three minutes to spend with the child during morning rounds, this compassionate doctor would enter the room, ignoring everyone there except for the patient. He would greet and touch the child, and for the next few minutes his attention would be completely on the person he was visiting. He does not wear the traditional Lab Coat or a tie, explaining that they are seldom cleaned, and are loaded with germs.

This account of Dr. Kamen appears on *Wiki.com*:



His brief visit seems much longer to his patients, as he turns to leave, he acknowledges others in the room, and then he once more smiles and says good-bye to the patient.

Lab Coat or not, Dr. Kamen is a true Rock Star – devoting hours to the SSP encouraging and inspiring the Survivor Advocates to view their activities and their focus on patients, caregivers and cancer differently.

During an Ice Breaker exercise, I spoke with a lady who was very personable, down to earth, and was genuinely interested in what I had to say about my cancer experience as well as other details, she spoke a little of her research at the National Cancer Institute. An enjoyable few minutes’ conversation and then we shifted to other people to get acquainted with. Her credentials

included: Chief of an entire cancer section in a cancer research facility; the person who discovered the first metastasis suppressor gene. She was involved in the Biomarker Research Program that was underway at NCI, and she was tremendously excited about it. As we chatted for those few moments, I knew that the next time someone lamented on the Kidney Cancer Member Forum: “*Somebody Needs to Do Something*” I would be able to “look them in the eye” and to post a reply that: Patricia S Steeg, PhD – Rock Star in a Lab Coat and countless others like her are “doing something.”

In a larger room of the convention center a topic was being presented on which I had a great deal of interest. I knew the language would be technical, and that I would have a degree of difficulty in understanding some of the material – but I felt that it would be worth the effort. In the meeting room, I noticed two research scientists whose ID badges bore the name of the pharmaceutical company that manufactures the targeted-therapy medication that I have been taking for over three years with progression-free results. As we got involved in a conversation they began excitedly asking me all sorts of questions; similar to a Rock Star asking a member of the audience to critique the performance. Suddenly, we had to stop the conversation; it was time for the lecture (actually past the starting time! we were holding things up) –in parting, the Rock Stars thanked me for my information and commented that it was great to be able to hear first-hand from someone who was taking the product that they had worked so hard on. While the lecture was good; I received some useful information –I actually received greater lessons from the conversation with the Researchers:

- Many researchers would love to have more interaction with people who can provide them with meaningful information from a survivor standpoint.
- There is a level of genuine interest in most researchers to eliminate the Shadow of Cancer

Anyone who has ever attended a Science Fair in the Gym of a local Middle School can relate to the next segment of this account very well. While the Rock Stars were occupied with performances and presentations on the floors above in the spacious Convention Center, there were a number of people who were “auditioning” in the basement (or the Exhibit Floor according to the maps). Flanking the hundreds of exhibitors who were offering information on all sorts of must-have-cutting-edge-stuff for the discerning researcher (probably someone was even selling a line of Lab coats) was row after row of boards for Poster Presentations.

Suddenly something clicked: the tubes in the backpacks that I had observed when I first entered the Convention Center contained *posters!* – Posters that were the result of hours of research, of study, of hopes, and of hard work. These Posters were being brought to display and present at the Annual Meeting of the AACR; an event something like the *American Idol* of Cancer Research. These posters were in the possession of the rising generation of researchers aspiring to become Rock Stars in Lab Coats, hopefully containing ideas that may result in *the*

Patricia S Steeg, PhD
National Cancer Institute



Most cancer patients succumb to direct or indirect effects of metastasis

Direct organ compromise
Consequences of treatment
Paraneoplastic syndromes

**“Excuse me, but have traditional therapies cured cancer?
It’s time to do something new...”**

2010 Lecture to SSP

breakthrough, the key, the cure, or perhaps “the removal of the shadow of cancer” that Dr. Barker so confidently predicted that would be accomplished.



Somewhere presenting a poster at the 101st Annual Meeting of the AACR could be the next Don Coffey; someone that was filled with determination and drive, refusing to accept rejections and failure, destined to become a Yoda in the field of research. How many would have the tenacity of Thomas A. Edison who is reputed to have responded to the question, “How does it feel to have failed to produce an electric light bulb?” With the reply: “I haven’t failed – I have discovered 5,000 ways that will not work.”

A “stroll” down the long aisles of the posters on display is similar to walking down a long 15 foot-wide hallway lined with advertising posters on both sides, with occasional groups of people huddled together around one of the posters; or one or two people stopping, looking, listening to the person who is ready and very willing to describe the story behind the poster. It is an audition; a performance that could stir the interest of someone who has a position open for a promising researcher, or an individual with connections to available grants for the furtherance of this study. The posters each displayed only once for a three-hour period on one of the days of the meeting run the spectrum of cancer research. There was no way that I could review or look at every poster – too many other things needed my attention. The time I did spend and the walk-away impressions that I received were of great value; I could honestly reply to somebody that there are a lot of people “doing something” to bring cancer under control. Two of my experiences are presented here:

He sat in the chair next to the poster – a sheet of laminated work that had numerous images of arms that were filled with green lines of various sizes and dimensions. As I stopped to look at his work, he rose and stood silently and respectfully with an obvious desire to answer any

questions or to explain the merits of this work. This young man stated that he had found a procedure that could predict who would be more at risk of developing lymphodema as a result of breast cancer surgery. His research indicated also that many times if the surgical procedure were done in a slightly different manner would the chance of the development of lymphodema would be greatly reduced. Even to a lay person with limited knowledge of the topic, I understood that the development of lymphodema in a person who had undergone an otherwise successful procedure meant that this condition could have challenges and problems that would affect them the remainder of their life. This technique could perhaps avoid that situation in many people.

She stood at the ready beside her poster; a display of studies of animals with implanted tumors that had been injected with a contrast medium and then scanned. This was a good basis for the term “Rat Doctor” – as she and countless others around the world involved in the field of cancer research used animals in part of their studies. Our conversation evolved to a discussion of her research facility, one that I had heard a lot about. As she began to talk about the facility and



to move away from the features of her poster project, she was no longer speaking on a single subject of discovery and research – she was talking about the environment in which she spent much of her life. She told of a new piece of scanning equipment that was being installed in the lab in which she worked – no longer would her specimens have to be transported down the hall, up a couple of floors to be scanned for changes. This new installation would not only save time and inconvenience, it would reduce the effects of movement, delay, and trauma to her specimens.

While she expressed a great deal of enthusiasm about the present project, she was probably more enthused and excited about the future with the installation of the new equipment and the increased reliability of data it would bring to the researchers in her area.

There was another poster presentation at the Annual Meeting. This event was not extensively publicized or highly attended. It is not readily known how many of the 17,000 people in attendance visited this poster session, or the number of Rock Stars that stopped by to take a look at what was inside the double doors of the Scientist ↔ Survivor Poster Room. What the sessions lacked in publicity and attendance was more than compensated for in enthusiasm and passion. The poster sessions were held in three groups, with about a dozen presentations done in each grouping. Participants were allowed two minutes to talk about their organization and/or the advocacy work they were involved in. Two minutes is not a lot of time to disclose the hopes, dreams, successes and failures of the work of a Survivor Advocate. While these presenters may not have been aspiring Rock Stars they were committed to their cause(s).

Whether it is involvement in a grassroots organization like Brown Buddies in Memphis, Tennessee where Faye Hollowell founded a group of advocates to “Be a Buddy” and to make a difference in the lives of cancer patients and their families; or Kate Murphy who helped to begin the C3- Colorectal Cancer Coalition and other organizations, the stories and experiences of Survivor Advocates are difficult to compress into such a small segment of time.

It is possible that Faye has never worn a Lab Coat in her life: a quick search on *Google* reveals nothing about Faye or Brown Buddies, and yet in Memphis, Tennessee (perhaps *the* birthplace of Rock and Roll), Faye and her colleagues have impacted many lives through their efforts in an up-close and personal way as she carries the universal message of care and

compassion to families whose lives have been impacted by a diagnosis of cancer. To those families, the song of hope and companionship allows them to connect more securely with the messages that those in Lab Coats will convey in the cancer journey. Faye, to the people that she comes in contact with – is a Rock Star.

Kate's advocacy covers a different spectrum of the cancer journey – handling the duties of C3's Director of Research Communications, "she provides a voice for patients in many national settings. Knowledge, she says, can break the desperate cycle of helplessness and hopelessness." (C3 Staff, 2010) In an international setting instead of a Memphis neighborhood Kate, like Faye, is striving to break the desperate cycles of emotional turmoil through her work.

I was able to attend all of the Advocates' Poster Presentations. While I had wanted to have an opportunity to meet and to speak with each of the advocates and the mentors in the SSP (because of each of us going in so many different directions and with different schedules) there were some advocates and mentors with which I never talked to at length during the entire meeting. At least I could hear from all of the advocates during their Poster talk. People who were reserved and normally quiet became animated and excited when talking about their advocacy. While everyone was involved in Survivor Advocacy in different ways and levels, their passion and commitment to their work was tremendously uplifting and inspiring to me. We could have literally spent days talking about our own experiences as we reached out in different ways to "break the desperate cycle[s] of helplessness and hopelessness."

I was in the first group of Advocates for the Poster Presentation, and I was very honored and pleased that a special Rock Star and his lovely wife were able to attend that session. Among the many exhibitors at the Annual Meeting was the Kidney Cancer Association. Bill Bro, the KCA's CEO and his wife Jo were able to leave the exhibit long enough for the poster session in which I was able to give a brief overview of the work, vision and worldwide impact the KCA has on those who are affected by Kidney Cancer whether in a survivor/caregiver setting or in the research and treatment setting.

The hours of the meeting came and went; topics were covered that added to each of our knowledge and gave us extra abilities to address the issues of people that we would come in contact with through our advocacies. Our minds were saturated with information from Rock Stars, Rising Rock Stars and the Rock Stars disguised as Mentors for the SSP as well as much information from our peers. When I heard Merv Williams speak during his Poster Presentation, this Arizona survivor of Prostate Cancer that had been involved in the Real Estate Profession for two decades gave a very rousing and inspiring talk. His effort to raise awareness of Prostate Cancer, particularly among African American Males in many different venues is making progress. During the rest of the meeting, as I teased Merv of being able to sell Arizona ocean-front property with his presentation skills, we had an opportunity to share some of our advocacy experiences.



Kate



THE CLOSING CELEBRATION

Insomnia saves the day

We gathered in the same room at the Grand Hyatt for the Closing Celebration of the SSP as we did at the Opening Ceremony. I had accumulated many clues in the days since that first encounter in this room filled with people who were incredibly talented and dedicated – the clues,



scribbled in my Carolina scrawl (which rhymes with my drawl) filled 2 ½ legal pads plus several napkins and scraps of paper; probably more notes that I took in 4 years of high school. It was time for another meal, some talk, and then the Work Group Presentations began. All week we had been preparing for these 10 minute overviews, and almost at the last minute we were given approval to use PowerPoint Presentations. Suddenly, the material that I and the group had worked on assembling was not quite as important as putting together a workable slide presentation that could better display key facts and insights. I had received an e-mail early in the morning on Closing Day from group member Dr. Jane Perlmutter.

Jane had difficulty sleeping the previous night, and had put together a PowerPoint presentation on our topic – “just in case we needed it”. That 3:00 AM effort on Jane’s part

wound up as the backbone of our Group’s Program on

Biomarkers. While I was not familiar with some of the information on the slides – having been in other lectures than Jane, there was enough material there to provide an enlightening 10 minutes of facts on biomarkers.

Back on Day 1, I had asked Peggy Devine, our Advocate Mentor about the best “delivery style” to use during the presentation – she replied “be yourself.” The audience got just that – I imagine one of the things that Don Coffey and I had in common was our delivery style. While I am not a Rock Star by any stretch of the imagination, my “Carolina Country” approach has always been my most comfortable method (Don’s is basically the same since he is originally from Eastern Tennessee) I didn’t use any Slinkys™ or wind-up toys, but those life-long reruns of homespun philosophy on *The Andy Griffith Show* gave me a few props.

I recall the first time I looked at the Member Forum of the Kidney Cancer Association; it was packed with lots of good clinical information. But it was just that—basically clinical, impersonal, and suffocating in bland facts and figures. It was accurate, but it was cold and stuffy. I signed up for the forum, and promptly “opened the windows” on the posts I made: “*I understand that stuff makes your mouth sore, but do you also use that hot sauce and chili powder on everything you eat honey?*”

In no time, the stuffiness seemed to vanish... but honestly, I had little to do with the other members starting to loosen up – it was something that they wanted to do all along. The member forum has become a much friendlier place – it is still filled with information that is medically and technically correct, but it also serves as a place where the participants can help one another break or deal with the “desperate cycles” of survival and caregiving.

When it came time for our group's presentation, the audience received less clinical information but more "cycle breaking" information: the promise that developments in Biomarkers will allow for more truly personalized care, not only of those who are receiving treatments for a cancerous condition, but in the ability to determine who is most susceptible for a disease. Cancer diagnoses for the most part today are clinically driven as the result of displayed symptoms. While there are many early detection tests that are available i.e. breast, colorectal and prostate that can greatly reduce the incidence of cancer and the burden of progressive disease and mortality if utilized by the public, the development of more biomarker and at-risk predictors will serve to increase the awareness of early detection and preventative measures.

The paradigm shift in cancer research, the utilization of the insights from the Physical Sciences, the fact that technology has finally gotten to the point which it can prove or disprove existing theories (some have been stated for centuries) and to search for new ones adds an exciting new dimension to the realization that breakthroughs are poised to take place.

As the AACR and researchers around the world pursue personalized treatments and diagnostic tests for every individual, it may be interesting to consider this statement by Sir James Paget of the Royal College of Surgeons as he addressed the *Abernethian Society* in 1885:

As no two persons are exactly alike in health so neither are any two alike in disease; and no diagnosis is complete or exact which does not include an estimate of the personal character, or the constitution of a patient. (Who Named It?)

The impact of the SSP on the advocacy projects that I am involved in is already yielding results. Some of the lines in the songs of the Rock Stars have become incorporated in my approach to dealing with situations: I appreciate the idea of *treating people – not cancer*; I understand that our brain and eyes can provide great insight in getting in touch with ourselves and others as we strive to assist in the cancer journey, and I firmly believe that the shadow of cancer is slowly being dissolved as we become enlightened by research and understanding.

Through contacts with fellow advocates (in parenthesis) at the SSP, other developments are starting or have been advanced: The *Bladder Cancer Advocacy Network* (Claire Saxon) will have an Exhibit at the 4th Annual North Carolina Cancer Survivorship Summit in June 2010, and the *Prostate Health Education Network* (PHEN) will have a Father's Day Rally at the Closing of the Summit (James West); Presbyterian Hospital, Charlotte, NC is in contact with *Yoga Bear* about the possibilities of being a resource for yoga classes from survivors who contact *Yoga Bear* (Jason Zimmerman); and the Western Coordinator for The North Carolina Comprehensive Cancer Program has an additional advocate to contact for the Eastern Band of Cherokee Indians to work with in developing programs through networking with (Celeste Whitewolf) who lives in Oregon.

Those items are some of the things that I can use in my everyday contacts with survivors and their caregivers. I no longer look at a person with pancreatic cancer the way I used to: my paradigm has shifted, for I have met and talked with an eight year survivor (Brenda Coleman) who is vibrantly alive and active in the *Pancreatic Cancer Action Network* as well as assisting patients, support resources, and research efforts through a website and other means of communication. I have a better understanding of the issues men face in dealing with prostate

cancer; and despite the Pink Aura that surrounds breast cancer, I can better appreciate that in spite of its many treatment modalities and success in survivorship there is a lot that is still unknown about some of its subsets and characteristics.

The enthusiasm of the “Basement Gang” of Rock Star wannabees promises to advance the pace of *Conquering Cancer Through Discovery Research* to an even faster tempo than the relentless march forward of the past Half Century. Technology is allowing more complex tasks to be done faster and with a higher degree of efficiency; the main Rock Stars of today are very intent on changing the strategies of cancer research by adding additional Scientific Disciplines to the mix. Coordination as well as cooperation between the various arms of research is being drawn together in a unifying force as never before. Subtle changes in the human genome are measured in nano-seconds and nano-particles; allowing a more concise picture of what is happening, and to come up with methods to respond, or even better to prevent changes that can become precursors of cancer. To a cancer researcher that retired in the mid-Twentieth Century the current landscape would be very unfamiliar. It is in a positive direction that those “in charge” of the Research; the Rock Stars in Lab Coats, are leading this effort.

As this process of Discovery Research unfolds it will be prudent for the Survivor Advocate to become more aware of the rapid developments that are taking place in order to better inform the groups that they are involved with. It stands to reason that earlier detection, preventive screening and clinical trial enrollment will be even more important in removing the shadow of cancer from our midst. As the technology and capability is developed in the labs and clinics, someone has to usher the “audience” in to the songs of care and cure of the “Rock Stars.”

Much of that task will fall upon Survivor Advocates and the organizations with which they interact. The attitudes and perceptions of the general population will have to be refocused on the possibilities that now exist and will exist – not on the failures in the past that were often the result of lesser information and practices. The news of a medical condition for which there was little that could be done a year ago that becomes a treatable, curable situation today will have to be imparted to those affected by that condition. Additionally, the news of hope will have to be presented in such a way that it will displace and overcome the image of failure and hopelessness that was yesterday’s fact and reality.

Just as the Scientist \leftrightarrow Survivor Program helped to bring about a change in the urgency of what researchers are focusing on and doing the mantle of change and urgency now falls upon the Survivor Advocates to increase participation in clinical trials, better diets, more exercise, and a host of other things that can be carried out by individuals, groups and organizations. It falls upon the Survivor Advocates to work hand in hand with government and industry to help to create and maintain a culture of change and continuing progress in research.



It's OUR TIME



Yearly:
 Cancer Kills More Globally than HIV, TB, & Malaria Combined

560,000 died in the US in 2009--- that equals 3 747's crashing each day

Drug Development: It takes 5-7 years for a drug to complete the clinical trials process—of 5,000 to 10,000 compounds that may work... 250 may go to preclinical testing... 5 may get to clinical trial stage....

A typical Smoker ACQUIRES one MUTATION at Cellular level for every 15 Cigarettes SMOKED

The average MELANOMA Cell has more than 30,000 point mutations

1 Drug will be Approved

Cost... \$1,000,000,000 (1 BILLION DOLLARS)

A Recent Survey Found:

- 85% of patients were interested in a clinical trial
- 9% were told that it was a possibility
- 3 to 4% were encouraged to participate

There are more than 850 drugs in the investigational pipeline

Information on this page from:
 AACR's Video *It's Our Time*
 First Aired at the Opening Ceremony of the 101st Annual Meeting
 view the complete video at:
<http://www.youtube.com/watch?v=3pobQRfz0No>
<http://www.aacr.org/home/public--media/multimedia-/aacr-videos/its-our-time-video.aspx>





My Support Group: Amie and Peggy



Yvonne: My Wife and CareGiver

Scientist-Survivor Program Alumni - 2010



Observer's Summation

As a twelve-year survivor of Renal Cell Carcinoma it is indeed encouraging to have been able to witness the developments in technology, medicines, treatment options and other advances in the past dozen years. Perhaps even more significant is that the quest continues despite the fact that several major advances have taken place in the last few years. Those who do research and who do medical practice with patients that are diagnosed with cancer are relentless in their pursuit of tools to better apply the options that we now have. Their quest for finding commonalities that will allow for optimum treatment methods with minimum side effects has yielded a few promising clues. Their determination and spirit of cooperation is on the threshold of yielding even more knowledge about the characteristics and subtle differences in tumor types and variables in the patient as well. This yielding will improve the chances of survival, the quality of life, and perhaps even freedom from the affliction of Kidney Cancer and all other cancers to those who will be diagnosed in the future.

For those that live each day with the hope that breakthroughs will come sooner than later, it is with a deep sense of gratitude and appreciation, thanksgiving and praise that I express my thanks, my warmest wishes and best of success to all who endeavor to find answers for many; and for the survivors, caregivers, families and friends that so courageously continue on the journey of survivorship, I offer my encouragement.

Warmest Wishes – Best of Success

Mike Lawing – Forest City, NC

With Grateful Thanks to the AACR – Mike



Closing Session: Dr. Barker's Remarks

References:

AACR. (2010). *Survivor Advocate Program Materials*.

Barker, A. D. (2010, March 23). Deputy Director, National Cancer Institute. *Testimony Before the Subcommittee on Health Committee on Energy and Commerce, United States House of Representatives*. Washington, D.C., USA.

Motzer, R. J. (2010 Annual Meeting). Mechanistic Approach to Targeted Therapy for Advanced Kidney Cancer. *AACR - New Concepts in Organ Site Research Sessions*.

Physical Sciences in Oncology - Executive Summary. (2010). Retrieved May 12, 2010, from National Cancer Institute: <http://physics.cancer.gov/about/summary.asp>

University of Louisville/Research Louisville. (2010). Retrieved May 11, 2010, from researchlouisville.org: <http://researchlouisville.org/previous-years/keynote-speakers/2000-dr-donald-s-coffey.html>

AACR Mission: The mission of the AACR is to prevent and cure cancer through research, education, communication, and collaboration. Through its programs and services, the AACR fosters research in cancer and related biomedical science; accelerates the dissemination of new research findings among scientists and others dedicated to the conquest of cancer; promotes science education and training; and advances the understanding of cancer etiology, prevention, diagnosis, and treatment throughout the world.

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Mike Lawing is a Volunteer with:



