



Tools for Your Journey: Courage, Faith and Hope

ZORA BROWN

*Presented at the 8th Annual Conference for Young Women Affected by Breast Cancer
February 24, 2008*

JEAN A. SACHS, MSS, MSLP: Now I have the pleasure of introducing Zora Brown. I think ... it's important to remember ... the women that came before you; that paved the road to make this conference and so many other things possible. Zora was one of those trailblazers. She's still blazing trails today.

Zora Brown is a 26-year breast cancer survivor, which is amazing, and [an] ovarian cancer survivor, as well. (Applause) She is currently the director of health and cultural affairs and special assistant to the CEO of INTEGRIS Health in Oklahoma City. She also is the founder of the breast cancer research committee Rise, Sister, Rise. [She] has done so much to bring attention to breast cancer in African-American women, and [she was] doing it at a time when no one else was doing it. We have learned so much from her. I think she is a wonderful closing speaker to bring us all together, which is what we always want so we don't have people leaving this conference thinking, "Oh, my God, I'm so overwhelmed. I just got so much information, and now I've got to go back and figure out how to move on." I think Zora will be the perfect inspiration for that. (Applause)

ZORA BROWN: Thank you so much, Jean. This is an incredible opportunity for me to come together with the young women who have been affected by breast cancer.

One of the things I want to tell you this morning is that there are lots and lots of things for you to look forward to. One of them are these. (Laughter) The other one that I have looked forward to this year with increasing delight is cellulite. I never thought I'd get to that point. (Laughter) But I want to tell you that this is an incredible opportunity for me. While I am not 26 years old, I am a 26-year survivor, actually a 27-year survivor, of breast cancer. (Applause/cheers) Just to look out and see all of you — I can tell you, you have a lot to look forward to.

And I just, this morning, want to thank God, thank Him, for my presence at this important conference. It reminds me that there is nothing quite so powerful as a gathering of people united by a noble cause and a common commitment. Tools for your journey are courage, faith and hope. I am grateful to the Young

YOUNG WOMEN UNITED AGAINST BREAST CANCERSM

Survival Coalition [<http://www.youngsurvival.org>], Susan G. Komen for the Cure [<http://cms.komen.org>] and Living Beyond Breast Cancer [<http://www.lbbc.org>] for permitting me to be part of this important conference. I am equally grateful to the other presenters [for] their willingness to help expand our knowledge of breast cancer.

I am grateful to my fellow cancer survivors and your supporters, family and friends for sharing with me your courage; to my fellow advocates for providing increased inspiration to do the work that we must do in support of cancer survivors, not only [in] our nation but throughout the world; to the cancer researchers for continuing the fight in advancing medical knowledge and providing better outcomes for patients; and to the benefactors — those all-important benefactors, foundations, and funding sources. I particularly thank you. Without the money required to pay for the research and development, I daresay that I might not be standing before you today. So thank you. Thank you all very, very much. (Applause)

This conference reminds us that, in our crusade against cancer, we are faced with a most formidable foe. We fully comprehend that cancer is not only insidious, [but also] pervasive. Although some are more susceptible than others, we are all at risk for developing cancer. We have come to address these facts with clear-sighted vision and to fashion appropriate responses to their reality.

It is not my purpose to encumber you with a delineation of facts because you've heard all those this week. Rather, it is my purpose to promulgate the power of hope; to embolden you to make hope a reality.

The promulgation of hope proceeds first and foremost from an acceptance of life with all of its uncertainties. The cancer survivor knows all too well that there simply are no guarantees. The cancer survivor knows that life promises none of us a bed of roses. In short, the cancer survivor knows, better than most, that to be mortal is to suffer the vicissitudes of life and to accept changes in our lives that are far different from those that we had envisioned.

The ability to make hope a reality despite illness and adversity is the very stuff of which life is engendered. In the immortal words of the Reverend Martin Luther King, Jr., “We must accept finite disappointments, but we must never lose infinite hope.” My own sense of hope despite adversity is, of course, born of firsthand experience. I emerged from that group of especially high-risk cancer survivors: my great-grandmother, my grandmother, my mother, my three sisters, three of my nieces and I have all suffered the ravages of cancer.

I was first diagnosed with cancer at the age of 32, and [I] subsequently underwent two separate mastectomies for breast cancer. In 2005 I was diagnosed with ovarian cancer. These are the stark realities of my personal and family history. I don't relate them to solicit sympathy for my personal lot. I relate them only to buffer my firm conviction that cancer need not be an automatic death sentence. I relate them to support my personal belief that the difference[s] between death and survival may well be the power of prayer, the capacity of hope and the ability to expand our knowledge of this disease.

In strengthening our sense of hope, we might reflect on my own story and the story of my family members. Despite my high-risk family history, my grandmother lived with the disease until the ripe old age of 94. (Applause) My mother passed away last August at the age of 91. (Applause) My sister Joyce just celebrated her 71st birthday, and [she] was treated for stage IV ovarian cancer more than 20 years ago. (Applause/cheers) And I, having been diagnosed with the disease more than 27 years [ago], stand before you happy, whole, filled with hope — not only for my own future, but [also] for the future of cancer survivors everywhere, particularly those members of my family [who are affected by it]. The good news is that I am but one of 12 million cancer survivors in our nation today. In strengthening our sense of hope, let us reflect on those 12 million survivors, each of whose life is a lesson in hope.

Ultimately our purpose for coming together is to learn and to provide answers [about] what it means to have a first-degree relative who has been diagnosed with cancer, to get the latest news about cancer treatments, to know exactly what preventive screenings are, to understand the importance of genetic testing, to learn the connection between obesity and cancer, to comprehend why smoking is so hazardous to our health and [that of] those around us and to find the knowledge, and then the courage, to participate in clinical trials. And in the African-American community, we have got to let the Tuskegee experiment be [a] footnote ... in our history and begin to understand that it is important for all of us to be included in cancer trials.

Two years ago when I was diagnosed with ovarian cancer, I was offered a range of treatment options. My oncology team wanted to give me the survival statistics based on treatment. I ultimately decided on the treatment that resulted from the clinical trial that my own sister was involved in more than 20 years ago. That trial is now the gold standard for ovarian treatment. Ten years ago I was able to take 12 of my adult nieces on a retreat to educate them about our family cancer history. The impetus was to ensure that they

were equipped to deal with a cancer diagnosis. Since that retreat, three of my nieces have been diagnosed with breast cancer. Most of my nieces are participating in clinical trials.

Ours is a formidable task, but we keep on going, and I submit that the thing that keeps us going is our infinite hope for the discovery of a cure. Should our hope begin to wane, I remind them that we should not impede our journey by reflecting on the rocky road that lies ahead. We must revitalize our hope by focusing on the roads that have already been hewn straight. While we have not yet discovered a complete cure for cancer, our crusade against the disease is far from lost.

As a result of our crusade, we have witnessed unprecedented advancements in cancer prevention and treatment. As a result of our education initiatives, the secrecy and shame that once shrouded this disease have been irrevocably stripped away. Unlike our parents and grandparents, we no longer feel that contracting cancer is somehow the result of our own weakness or a form of retribution for a sin. Rather, because of research and clinical trials, we now know that cancer is a clinical illness that can strike anyone irrespective of age, race, education or social status. Thousands of individuals who, in the past, would have concealed their illness are seeking preventative measures in treatment. This in itself is an enormous, enormous achievement.

As a result of the work of advocacy groups like the [Susan G.] Komen [for the Cure] [<http://www.komen.org>], LBBC [Living Beyond Breast Cancer] and you, the Young Survival [Coalition], a number of free prescreening tests for high-risk patients are now available; cancer prevention trials and studies are inclusive of all races and income brackets; [and] our army of researchers has isolated the BRCA1 and [BRCA]2 genes — a discovery that holds enormous promise for the early identification of breast cancer in high-risk women. In the last decade alone, mammography screening has become so refined [that we are able] to identify 90 percent of cancer cases.

We have expanded treatment options for breast cancer. Women are no longer exposed to the agony of undergoing surgery and, depending on the findings, awakening to find a breast removed. Rather, we are given options. We are told that we can have the option of choosing between mastectomy and lumpectomy, radiation as opposed to chemotherapy. Bilateral prophylactic mastectomy is yet another option for consideration for particularly high-risk women. And, depending on the cases, many women have the option of forgoing surgery altogether in favor of drug therapy.

The research from which these developments spring goes on with increased scrutiny even as we gather here. And so, my friends, rest assured that our crusade against cancer has wrought extraordinary results, results that bolster our hope immeasurably. I hasten to add, however, that hope is never passive. On the contrary — implicit in hope is the spirit of activism: a determination to stand at the helm of one's own circumstances, to call the distinct nature of one's own adverse conditions by name and to commit to life despite the ramifications [of those conditions].

Speaking to the practical manifestation of hope — we are reminded that hoping means seeing that the desired outcome is possible, then working to achieve it. Such a view places much of the responsibility for survival squarely on the shoulders of the survivor. When a survivor is diagnosed with cancer and chooses life, she learns as much as she can about the cancer disease, learns family history, assesses the level of risk and shares this information with her physician. More importantly, we focus not on the prospect of death, but on the renewed opportunity to celebrate life — not a life that is compromised or somehow impaired, but a life that is simply different; different from the one [that had been] envisioned, but no less beautiful and valued.

In our confrontation with cancer, our sense of hope is strengthened by the knowledge that we do not walk this journey alone, but are bolstered by family, friends, community and advocacy groups such as Living Beyond Breast Cancer and Komen. We embody a hope that helps us to accept change and adversity as a part of the mere fluctuation of life, to know that the unexpected circumstances of life render us no less valued as human beings and to accept these changes as a manifestation of the unique people that we are. Lani Guinier said, upon the debacle of her political [nomination as assistant attorney general] to the Justice Department — and I believe her statement applies to us today: “We are survivors, not victims, and we have to take a stand ... that allows us to move from being the victim of other people's decisions to the architect of our own well-being.” So the concept of hope often directs the survivor beyond the plight of his or her own particular disease. Hope, at its best, often subjugates individuals and individuals' needs to the needs of others, thus edifying the needs of both and improving cancer care for all.

It was just this manner of hope that led us to found the Breast Cancer Resource Committee and its support group arm, Rise, Sister, Rise. Our support group proceeds from the realization that breast cancer is more than a physiological manifestation. On the contrary: it is a disease that permeates every facet of a woman's life. In founding the Rise, Sister, Rise support group program, we wanted to address the personal, familial, physiological and practical needs of breast cancer survivors. Since its inception, we

have aided thousands of individuals, breast cancer survivors and their families, across this country. We [have] provided them with information on clinical trials [and] new therapies and treatments, counseled them on insurance benefits [and] follow-up care and comforted their loved ones.

More importantly, Rise, Sister, Rise provides a forum where breast cancer survivors can come together and tread on common soil. It provides ... shelter for those who must at times seem like the abandoned, warmth for the scientifically and medically neglected, security for the poor and, more importantly, hope for the otherwise hopeless. My own experience with Rise, Sister, Rise documents as its greatest value the knowledge that, in the struggle with breast cancer, no single individual walks alone. On the contrary — Rise, Sister, Rise gives survivors an opportunity to communicate with their fellow compatriots both common experiences and individual challenges. More importantly, it bolsters their hope.

I thank, with all my heart, each of you who has gathered here for this conference. You are both sowing and spreading the seeds of hope [that are] so vital to conquering cancer disease. My personal hope springs from my choices, early on, to embrace life despite all adversity. My hope has always been bolstered by the knowledge that, in my personal plight as well as in my advocacy, I am a sound and worthy human being. I lead not a less worthy life, [but] merely a different life than the one I had imagined. More importantly, altered as it is by the adversity and reality of breast and ovarian cancer, mine is a far more blessed and richer life than anyone could ever imagine.

Finally, let me assert that our hope for the future is grounded in our knowledge that, in coping with cancer, we are confronting more than statistics. Our hope is grounded in the beauty and possibilities of flesh-and-blood human beings — individuals who are mothers, fathers, grandparents, children, sisters and brothers, friends and caregivers; individuals who are wellsprings of human resources and resourcefulness; individuals who are national treasures, who, but for the susceptibility of cancer, might have achieved any heights, and who still can. Each of us is a unique individual shaped by the peculiarities of this distinct experience. Despite these experiences, let us embrace our individual lots as a mere expression of what it means to be mortal. Let us wrench from this darkest cloud the sometimes elusive ray of sunshine. Let us travel whatever our destined roads [may be] with a certain conviction that hope does indeed spring eternal.

The concept of hope need not be distant, elusive, ethereal or unfathomable. Hope, at its most practical level, means the ability to accept the inevitability of change, to accept the inevitability of adversity and to

embrace these experiences that make us the unique individuals that we are. In her book *It All Begins with Hope: Patients, Caregivers and the Bereaved Speak Out*, author Ronna Jevne writes that “serious illness is a journey, a hopeful journey, an unknown destination. In illness dichotomies are vivid. Hope is the space between symptoms and diagnosis, between diagnosis and prognosis. It is a wrestling match between science and compassion, between pain and grief. It is a dilemma between fearing to be alone and hungering for privacy. Hope is waiting for test results, waiting for appointments, waiting for organisms to heal and the spirit to rekindle. Hope is walking the line between constant probing and invasions and declaring, ‘No more. Not now.’”

As we continue on our journey to improving cancer care for future generations, let us look forward to the day when we can unequivocally say we have come this far by courage, faith and hope, and we have no further to go. Thank you very much. (Applause) There are questions to be asked and answers to be given, and I’m told that I’m to stand here for a few minutes and answer your questions. But also, we have a book outside, *100 Questions & Answers About Breast Cancer*, that I’m happy to sign for you.

JEAN A. SACHS, MSS, MLSP: Any comment or question?

WOMAN: Is there a website for Rise, Sister, Rise?

ZORA BROWN: Yes. It’s at bcresource.org. [Editor’s Note: as of September 2008, this Web site was unavailable.]

WOMAN: Hi. Thank you for your inspiring talk. I was wondering if you could talk more about the field trip that you took with your nieces and how you prepared them for learning about this and dealing with this family history.

ZORA BROWN: I must tell you that that was probably one of the single most important things that I’ve ever done in my life. Over a Thanksgiving holiday I learned that one of my nieces, the daughter of one of my brothers, had been diagnosed with breast cancer. Her mother and my brother were separated when she was a toddler. She knew about our family history, but her mother had convinced her that she was not at risk because she was a brother’s daughter.

I was absolutely mortified because I thought that, in spite of all of the advocacy I've done, I'd miseducated my nieces. So I was able, after Thanksgiving, to write a grant [proposal and submit it] to one of our dear friends in the pharmaceutical industry, and they provided me with the funding to take them on this retreat, to show them exactly what their risk factors were. We talked about genetic counseling, what the new clinical trials were. Since that time, three other nieces have been diagnosed with breast cancer. So it was, again, the most important thing that I've done.

I have to tell you that they are not slouches. When I told them that I'd like to take them on a retreat, they said, "Great. Take us to a spa." (Laughter) We did go to a spa, but we spent intense time — probably learning much of what you've learned here this weekend — about the importance of early detection [and] the latest treatments in breast cancer, as well as what it means to be at risk. They did go through counseling, which was quite traumatic for some of them. But they do understand what their risks are for breast cancer.

It led them to start another organization that is still ongoing and that I have sort of copied and taken to Oklahoma. That organization is called *SASSi* which is Sisters Accessing Skills for Survival and Intervention. It's geared toward a younger woman, and it's about lifestyle changes. It really is about all the things that one needs to do to empower oneself and to be able to live a healthy, whole life.

JEAN A. SACHS, MSS, MLSP: Any other questions?

WOMAN: I just want to thank you for your inspiring talk and [for] sharing so much about your family. I'm very moved, and I just want to thank you.

ZORA BROWN: Well, thank you.

WOMAN: I may have missed it, and you're talking about counseling, but did your family have genetic testing for BRCA1 and BRCA2? If so, would you mind sharing the results of those?

ZORA BROWN: Absolutely. Actually I'm very proud to say that my family was involved in the trial that led to the discovery of BRCA1. (Applause) We're very, very proud. Breast cancer exists on both sides of my family — my father's family as well as my mother's. There's a long history of breast cancer on my father's side of the family, so we were able to get tissue samples to use toward the discovery. We

work with Dr. Mary-Claire King, as many of you may know, as well as with the National Cancer Institute [<http://www.cancer.gov>]. So, yes, we did participate and [we] continue to do so.

WOMAN: I also have a couple of questions about the nieces. I'm very interested in that for a couple of reasons. My first question is, can you share the ages and what the range was?

ZORA BROWN: Yes. When I say they were my adult nieces — I have a lot of nieces. I have 18 adult nieces, and 12 of them [are] between the ages of 27 and 40.

WOMAN: Would you propose going younger than that in ...

ZORA BROWN: Oh, absolutely. I definitely would. The only reason we didn't is because the younger ones were still just a little too young, under the age of 21, and couldn't get out of school. But yes, I would. I've written up the model that we use, and other women are telling me that they're taking that concept to family reunions and other family gatherings to start the dialogue [about] family history and what it means to have a history of cancer.

The good news about the genetic testing is that not all of the girls in our family tested with the gene. But they do understand that they are not completely cancer risk free. So that's the important thing. It's just, again, opening up the dialogue.

WOMAN: I think you bring up a great point about family history because it seems like a lot of people I talk to didn't learn their family history until after they were diagnosed. It would have been helpful to learn that beforehand. So my last question has to do with looking at age, if you want to think of your community as your family, and how you can be advocates for younger girls — is high school age too young for this information?

ZORA BROWN: No, it is not too young. We are seeing younger women. I think I heard someone say this morning that within their group there was a 16-year-old. Within Rise, Sister, Rise we've had young women who have been diagnosed [at ages] as young as 18 and 19. So we do know that breast cancer doesn't have an age-specific body that it attacks. We know that the older a woman gets, the more susceptible she is to breast cancer, and [that] it's not that common in younger women. But I think just the knowledge and knowing exactly what the symptoms are could be very, very helpful to younger women.

And when I said I stole the *SASSi* concept from my nieces — I am now implementing a program in two high schools in Oklahoma City. It's for ninth grade boys and girls. We call the girls' program *SASSi*. It teaches them [about] leadership, healthy lifestyles and the importance of being involved in knowing what your community is about as well as what your own home life is about.

WOMAN: Good morning. A wonderful talk. I just had a question: Do you know of any new gene mutations that have perhaps been identified and if there are any ongoing trials or research into that, other than just the BRCA1 and the BRCA2?

ZORA BROWN: There are some new trials. Right off the top of my head I cannot tell you exactly what they are, but if you [visit] the National Cancer Institute's website and just plug in "gene mutation trials," I think it will give you that information. But I do know that there are ongoing trials. That's the beauty of being in this country and supporting our research: We are ever evolving. We are ever trying to improve what we already know. So, yes, indeed, there are new trials going on.

WOMAN: Good morning. Thank you for an inspiring talk. You speak about the importance of advocacy. Can you talk, for those of us who have not been very vocal advocates, about what you think some of the challenges are and things that we should keep in mind as we get involved with that?

ZORA BROWN: Well, the biggest challenge is always money if you're going to do it on a broad basis. But one of the [other challenges,] I think, is time. If you are doing it on a volunteer basis, there's always [the challenge of finding enough] time. But there is always room for advocacy, and I applaud you for even asking the question. I think if you have a desire, that fire in your spirit, and you know that there is more to be done and [that] can be done, there are no challenges or rivers you can't cross. So stay involved. We certainly need a louder voice.

I remember when Nancy Brinker started [Susan G. Komen for the Cure]. I was at the White House when Betty Ford was diagnosed with breast cancer, and there were little glimmers of conversations about breast cancer. Now it is just a wide-open conversation. But the conversation needs to go on because we continue to see younger women who are being diagnosed and saying, "Oh, no, not me. It could not have happened." But as long as we keep that dialogue open we're going to see improvements not only in

awareness, but also in the treatment and care of women who have been diagnosed — and also, hopefully, a cure.

WOMAN: As somebody who is BRCA1 positive and [who] had the opportunity to have a prophylactic bilateral mastectomy and a prophylactic oophorectomy, I just have to say a great big thank you to you and your family because, had you guys not been involved in that clinical trial, I, my sister and my cousins wouldn't be here in this generation. Until you mentioned that, I had no idea who they'd tested originally [or] how BRCA1 was discovered. So, for all of us in this generation, thank you. (Applause)

ZORA BROWN: Thank you very much. I have to tell you, too, that one of my sisters and several of my nieces have also had prophylactic mastectomy, and one of my nieces is celebrating her 18th year after having prophylactic mastectomy, and she's doing very well. (Applause)

WOMAN: Zora, I have kind of a research question. I know the association between BRCA1 and triple-negative breast cancer and the incidence of [it in] African-American women, particularly younger women. I don't know if triple-negative was really around ... well, it wasn't around 26 years ago. But do you know if that's the type of cancer that is in your family?

ZORA BROWN: You know what? We have estrogen receptor-negative breast cancer for the most part. Now, I don't know that that is necessarily across the board, because I have nieces who did not test for the gene who have been diagnosed with breast cancer. So I almost hesitate to even get into the "what type of cancer did you have" discussions. I just hope you understand what your risks are and that you know what your symptoms are and that you continue to do those preventative things and screenings and, if you find something, get it treated.

WOMAN: There is a lot of research looking at different genes and the types of cancers that you get. As an advocate, one thing you could do is donate your tissue to research because that's how they're going to run all these tests and figure this thing out. [A biopsy is] not a hard thing to [undergo]. Just tell them you'll sign a consent to donate your tissue to research.

ZORA BROWN: Absolutely. I am a strong advocate of clinical trials and am working with the National Medical Association [<http://www.nmanet.org>] on Project IMPACT [Increase Minority Participation and Awareness in Clinical Trials]. So if you know of anyone who is interested in knowing about clinical trials

that are involving African-Americans, I would highly recommend that you go to the National Medical Association's website and get involved with Project IMPACT because we do need to have more African-Americans not only in the research, but also in the trials.

I'm going to add a little bit of an editorial to that, because we've heard a lot [about] and we do a lot [of work in the area of] cancer disparities. A lot of times we continue to just focus specifically on the economic disparities or the lack of access, which are, indeed, disparities. But there is also lack of information and our being involved in clinical trials, and we do need to know what those commonalities are as well as what the differences are. That's the only way that we're ever going to find what I believe would be a complete cure for this disease.

JEAN A. SACHS, MSS, MLSP: Any other comments or questions? (Pause)

ZORA BROWN: Well, I thank you all very, very much. This is absolutely wonderful. It is so splendid to be here. Thank you very, very much. (Applause)

JEAN A. SACHS, MSS, MLSP: Well, with that ... I hope you learned as much and shared as much as I got to do. ... On behalf of Susan G. Komen for the Cure, our new collaborators and each and every one of you, I thank you for being here; I thank you for taking the time and [for doing] whatever it took to get here and I really look forward to working with you all in the future.

One editorial I will add to Zora's comment: There really isn't enough money for cancer research. One of the things we need to do is ensure that whoever comes into office makes cancer a priority. (Applause) Many organizations are working toward that goal. If you go to the I Vote for the Cure web page at <http://komenpolicy.org>, you can sign a petition to that effect and send it to everybody you know; it will start the dialogue. Thanks. (Applause)

WOMAN: I just want to add to that a thank you from the Young Survival Coalition for all of you being here. I know it was a tough time getting here, and I know that it's probably going to be a late night tonight by the time everybody gets home. I hope you've had a lot of fun. I know I've had fun, and I have met new people, and I've had a chance to get to know some of you and I appreciate that. If you're like me, though, you've had almost no sleep, so go home tonight ... and get a good night's sleep. Safe travels. We hope to see you all again next year. Thank you. (Applause)

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