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Breast Cancer Deadline 2020*

2015 Advocate Leadership Summit

Keynote Address: At the Midpoint of Breast Cancer Deadline 2020®

NBCC President Fran Visco

May 2, 2015

Good morning. And again, welcome. As most of you know, NBCC was founded in May, 1991; actually a small group of women came together a bit earlier than that to begin planning the idea of a coalition of groups from around the country to take on action to change public policy, science and health care and to give women with breast cancer a voice at all tables where decisions would be made that affect their lives.

My introduction to NBCC came in May of 1991, in Washington, DC, at the first organizing meeting of what was to become the National Breast Cancer Coalition. It has been quite a journey. How many of you were there at the May 1991 meeting? How many of you were part of the first letter writing campaign, Do the Write Thing? How many of you were part of the 300 Million More campaign, that launched the DOD Breast Cancer Research Program? The 2.6 million signature petition that led to the national action plan on breast cancer?

I get to stand up here every year for the past more than 20 years. All of you who have been there every step of the way, every difficult, controversial, painful yet glorious step, should stand up too. I applaud you. We all do. Everyone should. You see, we, together, have really changed the world of breast cancer. More so than anyone.

Think about it...

NBCC has a long history of being a leader in the world of breast cancer – taking on big issues, challenging business as usual, facing controversy head on and achieving success. Indeed, in many ways the entire history of NBCC has been about doing what everyone else says is impossible.

When we came together in 1991, we did not limit our vision. We wanted to do nothing short of changing entire systems of research, care and policy. And we wanted to do it through grassroots activism. We built this amazing network of advocates across the country, unprecedented organization, passion, courage. These were women--and men--from all walks of life, who were willing to share in and dedicate themselves to our mission. You must value and respect that level of grassroots commitment. You have to make certain the agenda you set, the actions you take are worthy of those advocates' invaluable time and effort. That anything you did would have enormous impact. We, NBCC, had gained the trust of those incredible individuals and organizations and we would never misuse it.

We set a mission to end breast cancer. And despite the incredible push back from many scientists, other breast cancer groups, and the government, all of whom insisted that you can never end breast cancer, we knew that had to be the goal. And we knew it could happen. You know, it never occurred to us back then that maybe we should have a goal of getting every woman screened, or making it easier to get drugs approved. Or end breast cancer for old women, or young women, or for a specific type of breast cancer. I don't recall ever having those conversations: we were in it for all women and men, to end breast cancer for everyone. And our movement allowed other groups focused on specific issues to spring up, and at the same time to come together under our umbrella for everyone. Our coalition is comprised of groups that focus on a variety of extremely important specific issues: young survival, HER2, metastatic disease, triple negative, disparities...and they should. But we must all come together to work on the overarching issues in breast cancer--on the strategy to end breast cancer.

Back in 1991, we talked about where to start. What would have enormous impact? We first took on getting more funding for research. We knew that private events, runs, dinners were important, but would never bring about the kind of money needed to make a real difference in science. We knew that could only be the federal appropriations process. So the first step of our strategy was to increase federal funding for research; of course we knew we didn't just want to throw money at the problem. We were strategic: how much money could the scientific community absorb in 1992? Where were they in the search for answers in breast cancer? We didn't want any of that money wasted. Our research hearings led to a plan for the government to spend an additional \$300 million, from \$100 million to more than \$400 million in 1992, and that launched the DOD Breast Cancer Research Program. This was something that had never been done before and was incredibly controversial: demanding that large an increase, there was opposition to that everywhere, Congress, the White House, other groups and then; looking at the defense budget for breast cancer funding? It made us quite a few enemies. But that did not stop us and we were successful.

We also didn't win any popularity contests when in our pursuit of access to care we dared to question the idea of federal funding for screening but not treatment. NBCC wrote and pushed the CDC Treatment Act, creating a system of access to care for thousands of uninsured women in this country with breast and cervical cancer. For those of you who were not there, you must understand that there was a great deal of opposition to our strategy. Other groups worried that what we were doing could harm the screening program. That "entitlement" programs should not be expanded. That there really wasn't a problem.

And then we pushed controversy even further.

We wanted to be certain that we had a say in how research dollars were being spent and what care women were getting. So we launched our education and training programs, of which Project LEAD® is the most well known. Unprecedented, difficult training to make certain advocates had a seat at all tables where decisions were being made and to make a real

contribution once there. Breast cancer advocates judging science? Challenging researchers? Yes!! All so very controversial. But we did it...

The fact is, controversy became an NBCC hallmark; not because we set out to be controversial, but because we approach problems in a unique and strategic way that challenges the status quo. Because we always ask: where is that enormous impact? We may take all of those accomplishments for granted now...we should not! So much of what is happening in breast cancer stems from those NBCC successes, and we continue to build on them.

At this year's Team Leader Training, one participant asked me a fascinating question: what was different back then, that we could accomplish so much? That we could get bills made into law? Change the way research was done? What was different? Sure, Congress was much less partisan; there were many fewer breast cancer groups and so not so much competition for attention. Many things were different.

And one very important thing: *we were different.*

We were willing to do whatever was needed. If we had to stand on street corners to get signatures on petitions, we did. If we had to challenge our Senators and Representatives, we did. We stood in the halls of Congress, outside committee rooms, taking abuse from angry Senators, we stood on the steps of the Capitol, and when we were told to move, we didn't. We did not care who invited us where, or whether we were the breast cancer advocate a Congresswoman called for a photo op. We only cared about getting that bill passed, about getting it done, about ending breast cancer. For everyone.

I suppose every movement gets soft. Comfortable, unfocused, scattered.

Maybe even pink and pretty.

It begins to celebrate the little things, because it is too hard to achieve the big ones. And winning anything, no matter how small, feels so good.

I believe we went through that phase, albeit briefly, but not that long ago. But we are still the National Breast Cancer Coalition. And so we took stock. In 2010, we asked ourselves: what are we doing that will end breast cancer? What value do we bring to the movement we started? Are we now just another group, allowing the status quo to lumber along, while each year 40,000 women and 500 men die of breast cancer in this country alone? If we dissolved tomorrow, what would be different?

We were proud of our work but had to ask, to what end? We had to go to an entirely different level. Is it enough to bring billions of new dollars to the scientific community? What had we truly accomplished?

\$3+ billion dollars for science through DOD alone, because of us, so many papers published-- and yet...so many lives lost and continue to be lost, new research mechanisms through our influence, but the same old questions get submitted, new treatments, not true breakthroughs, except perhaps in their cost.

Ironically, in our success the breast cancer movement created a new status quo. The scientific community took for granted that we would continue supporting the DOD program. But if they were to continue to support the program, we expected them to do things differently. At the same time, breast cancer had become big business. The real issues were obscured in a big pink cloud of awareness and fluff. With so many vested interests, we had to take a fresh look at everything. Yes, we succeeded in getting advocates a seat at the table, but who are they? Are they well trained? Do they ask difficult questions? Do they have an agenda other than ending breast cancer? What do we bring to this world and does our message get through all the background noise?

We knew that we had to change, regain our focus, and bring back urgency to breast cancer. And so we launched an innovative new initiative: **Breast Cancer Deadline 2020®**. We will know how to end breast cancer by 2020. We knew it would not be easy, and it hasn't been. We knew it would be controversial, and it has been. But we did it anyway because we know that a deadline changes everything. We knew we would be faced with much opposition, disdain even, dismissal. And we knew we could fail. Of course, you know, maintaining the status quo is a sure recipe for success. Setting your goal as the next baby step ensures success, or that if you do fail no one will notice. But it doesn't change the world. It would just be hollow success that belittles our mission.

But a deadline?

A deadline screams urgency. A deadline demands accountability. A deadline says we are willing to stake our reputation on succeeding. In short, a deadline changes everything.

We decided to focus on two areas: stopping women and men from getting breast cancer to begin with and stopping them from dying of it by figuring out how to prevent its spread. We all know why we have to do this. Despite years of campaigns to raise awareness, ever-expanding screening programs, increased fundraising efforts and research we are nowhere near where we should be in terms of preventing breast cancer and preventing deaths from it. It is true some progress has been made. We have extended life for some women with metastatic disease. Mortality rates have declined, but nowhere near commensurate with the investments made in research and awareness. Breast cancer remains the second leading cause of cancer death for women in the US, and the leading cause of cancer death for women globally.

In 1991, in the United States, 119 women died of breast cancer every day. 20+ years, and billions of private and public research dollars later, that number is 108. Every day. That's one death every 14 minutes. This year nearly 40,290 women and roughly 440 men will die of breast cancer in this country alone, More than ten times that figure worldwide.

By 2030 it is estimated that at the current rate of progress, globally 750,000 women will die. That should not be considered success – or even meaningful progress – by anyone’s standards. And this is an important fact: the incidence of women diagnosed with advanced breast cancer has not changed. Rates of diagnosis of truly lethal disease have remained stable since 1975. All of these reasons are why we launched **Breast Cancer Deadline 2020**[®].

Now we find ourselves at the halfway mark, five years in. What have we accomplished? We not only set a deadline, we developed a blueprint and a plan of action on how to achieve it. There are actions to be taken by government, science and advocates. We looked strategically at what each stakeholder group must do, and what they can do.

Yesterday you heard about some of our work, the Artemis Project[®], and the research collaborations we maintain.

I hope you realize that what we are doing is not just looking at a preventive vaccine or preventing metastasis, but we are challenging science as usual, the process, the agenda, the participants. Artemis is about questions we want answered and about how we need to change the system of research to get those answers and get them in less than a century.

It would be much more comfortable to take a different approach. Raise money to fund the research that the system wants to do. A system that excludes our voice, our needs. That seldom looks for enormous impact.

That however is not NBCC. Not **Breast Cancer Deadline 2020**[®].

In Artemis we have made incredible progress on the research side; bringing the right people together, to work on the issues we identify, innovative approaches, big questions, real solutions. The science is moving forward. We have brought about \$600 million for science from the DOD budget alone over the past five years.

We continue to expand the group of people working on the Artemis Project® and hold meetings with multiple groups of stakeholders to delve into the complex issues of immunology and tumor dormancy. NBCC trained advocates have played a vital role in the Artemis Project®. They are part of every team. And they take on complex projects. Searching the literature to identify possible vaccine targets; analyzing prevention trials in other diseases to figure out possible pitfalls and successful approaches; searching for resources like tissue, so Artemis research can move forward.

Many researchers want to work with us on the deadline. I have heard the scientists who attend our Summits, who work on the Artemis Project® with us, say how their involvement in this unique approach helps them think differently about their work. They have formed new collaborations that will get answers more quickly. They recognize that through the work of **Breast Cancer Deadline 2020®** they are able to participate in something that has been missing in breast cancer research: a true collaboration that rises above individual agendas to focus on the big picture of what is happening and with a laser focus on ending breast cancer. They understand that the goal cannot be an individual's work, or the next publication or grant, but rather on the only goal that matters, the real goal of saving lives.

As important as these projects are, our work over the past five years has not been just about more money for research, a preventive vaccine and preventing metastasis. Ending breast cancer is not just about research. It is also about changing the conversation, changing the focus of the rest of the breast cancer world.

Reinvigorating our groundswell of public support has never been more critical. NBCC has never focused on marketing itself, our structure: a coalition of organizations working together on the overarching goal of ending breast cancer is exactly what is needed to achieve that goal. You are the leadership of that network of advocates and you are the resource needed to raise the profile of the deadline everywhere.

Since the launch of **Breast Cancer Deadline 2020**[®], more than 420 organizations have endorsed the campaign, and that number continues to grow. This expanding list of endorsing organizations demonstrates the breadth and diversity of the breast cancer, women's health and health care advocacy community that stands behind **Breast Cancer Deadline 2020**[®].

We need you to get more organization endorsements: is your organization signed on? How many others can you reach out to?

At this Summit, and beyond, we are giving you the tools you need to make all of that happen. You heard yesterday from some of our advocate leaders about how they are helping raise the profile in their communities. Over the next two days, we are connecting you with the people who know how to do this and who have a proven record of success. Experts in creative solutions and grassroots organizing. We are arming you with knowledge on how to review proposals and scientific articles. We are making sure you are updated on the latest science. You will hear stories of how ideas that were dismissed made their way into the clinic, in Ebola, prostate and cervical cancer. Listen well to how those pioneers made the system work in those instances. And listen well to the problems with the system, sharing data, unhealthy competition. You will hear quite a bit about the newest headline in breast cancer: immunology. Listen well so we know what to ask, whether this is real and if so how to move forward. In this room today sits the group of leaders who can make deadline 2020 a reality. Only through our leadership will we achieve deadline 2020.

Our work has advanced a unique and innovative model of science that truly integrates people like you; trained patients and advocates. And we are applying that model to other questions. We continue to expand online and other accessible training offered by our Center for Advocacy Training. In March, with the help of the Georgia Breast Cancer Coalition, we piloted a world class community engagement model in Atlanta. You will learn more about this new approach later in the Summit and will have the opportunity to give input to NBCC.

We talked about the role of science and advocates, but what role should the government play in the deadline? Government has become increasingly complex, and bureaucracy stands in the way of real leadership to end breast cancer. So we brought together various experts to help us figure out government's role in the new reality. We designed the Accelerating the End of Breast Cancer Act to make certain our government took on its necessary role. With your help, we have been educating a new Congress and building broad bipartisan support for this legislation and on Tuesday, we will push even more to get it enacted into law. It took 6 years to get the CDC Treatment Program signed into law; we have been pushing the Accelerating Act for the past three, almost four years, so it is time, in this Congress, for it to become law.

This is the kind of work we must expand and continue if we are to change the conversation in breast cancer. Everything we do is in the context of ending the disease.

We are doing our part. Ultimately, though, success will depend upon those outside NBCC: the leaders in industry, in government, researchers – the advocacy community – all of you to do your part. It will depend on funding: the budget for our deadline work is \$150 million, and as I said yesterday, each Artemis Project® alone costs \$10 million.

You must have heard from others that a deadline for the end of breast cancer is not possible. I am sure all of you have heard that. It is not possible to know how to end breast cancer by 2020. Science doesn't work that way. Well, it should. Science must answer to us. We have to take what has been discovered over the past many decades of our fight and apply it to save lives, to end breast cancer. We have to ask the big, difficult questions.

The naysayers. They're out there, whispering in our ears: it is impossible, silly to try. I have actually been told that one reason some scientists do not like the deadline is because if they fail, it will turn the public against science and they will no longer support funding for it. Really?

We know that it is the failure to dream, to create, to take risks, to collaborate that will upset the public. It's being ok with baby steps that frustrates us.

What role will you play to create a world without breast cancer? Is the end of breast cancer your passion and your mission? You have to be all in, because this is really difficult, challenging, uncomfortable work. **Breast Cancer Deadline 2020®** is not about being comfortable. It is not a slogan. It is a strategic plan of action to disrupt the status quo and end breast cancer.

The fact is, over the past 20 years too many of us have become complacent. The initial dynamism of the movement; the eagerness to march, to shout, to push has given way to old comfortable patterns. Are we so enamored of basking in our day in the sun that we have lost our will to challenge, to question scientists and demand change from Congress? Have we traded it all so that we are polite company, suitable for a pink ribbon ceremony at our local breast center?

We all know that you don't end breast cancer that way, you actually become part of the problem. So how do we revitalize this movement? We are doing it in science. We need to do it everywhere else.

The women I met in that room in 1991 were not content with simply talking about what needs to be done: they carried that talk into action and launched this revolution that is the National Breast Cancer Coalition. 24 years later, NBCC continues to thrive, defying the conventional wisdom that so many competing interests could never stay united. Keeping the coalition together has always been challenging but it is amazingly gratifying work.

We knew it was never enough to simply demand change. We figured out what that change should look like and how to make it happen, we educated ourselves so we could become the change we demanded.

We disrupted the system in order to make it better: by significantly increasing funding, getting the DOD involved, putting lay advocates at the table with a meaningful role, demanding a say in what research happens, expanding access to care for the uninsured, telling the truth in breast cancer, no matter who pushed back at us--setting a deadline.

We constantly challenged ourselves to do better. To do more. Let's find the courage again. Now. Nothing is more powerful than grassroots mobilization but it requires 110% commitment from community leaders like you. Let's take the opportunity at this Summit to commit to new ways to infuse energy into the movement. Let's find ways to be visible, to ensure we are heard. Let's do good by being bad. In the words of Congressman John Lewis, let's get into good trouble. Let's not stand for the status quo at scientific meetings, but instead stand in a picket line with signs and banners: let's find ways to rile up the public; to educate them with facts rather than wrap them in the comfort of a pink ribbon or a simplistic sound bite. Let's demand that everyone answer the question: are you with us?

You are not doing this alone. You are doing it as part of NBCC. And at this Summit you will learn about how to do it, how to be disruptive to achieve social justice.

I am now a 27 year breast cancer survivor. I still get to be a leader in this collaboration of activists, survivors, researchers, healthcare professionals, policy makers, grassroots groups and national organizations that have come together as disruptive innovators for social change. We are many different stakeholders working together to achieve one mission. We know we are stronger together, and that real progress can be made if we use our collective power and focus on a plan of action to end breast cancer. You, like me, are here because you want to be a part of that.

Every year as I start to prepare for this meeting, I try to channel those NBCC leaders who got us to this point, those who have died, but whose vision, strength and commitment are still the base that holds us up. I think about Pat Barr, and her practical, sage wisdom, Kendra McCarthy,

and Gina Soffa, who were constantly poking me to see if we've sold out. I remember Carolina Hinestrosa, and Chris Brunswick, who I miss every minute of every day, their brilliance, strategic advice, friendship. Karen Noss and her quiet forceful leadership, Kathy Zeitz and her mind, Silvia Rickard, so many others. Everyone in this room has their own memories, the women and men they walked the halls of Congress with to get the CDC bill moving; stood outside the appropriations committee room with facing down senators, the women they danced with at our Advocacy Conference parties, the ones you did peer review with, marched to the White House next to. So many. As I have said many times in the past, we stand here in the shadow of those giants; and sadly with every passing year the list grows; far too many leaders gone. Isn't it time? The time has come to stop losing the women, and men, we love to breast cancer.

Together, we have accomplished so much. And together we will realize our greatest achievement over the next five years. We can achieve our mission to end breast cancer – with the right planning, passion, leadership and funding. It has been 24 years since NBCC was founded with a mission to end breast cancer. Yes we have done quite a bit, but we cannot lose sight of the fundamental mission of ending breast cancer. We simply must do more.

It is NBCC's history that best illustrates its future. Those women in that room back in 1991 were not a part of NBCC to cure their own breast cancer, it wasn't about them. They launched and nurtured this movement for their daughters, their granddaughters, their sons, for future generations.

We will know how to end breast cancer by January 1, 2020.

No one ever said our mission would be easy. No one ever said it wouldn't be a bit scary. But we have to do this because if we don't, who will? It's more than time.

Breast Cancer Deadline 2020®. You are the only ones who can make it happen.

Thank you.