



**Kim Thiboldeaux, CEO, Cancer Support Community
Remarks at Cancer Moonshot Summit**

Wednesday, June 29, 2016
Howard University, Washington, DC

Good Morning.

My name is Kim Thiboldeaux, CEO of the Cancer Support Community.

I want to first thank Vice President Biden and the Moonshot team for their work in delivering this important summit today.

I also want to thank you for including the Cancer Support Community – we are proud to be hosting 31 summits across the United States today at our Cancer Support Community Centers where we serve thousands of patients and their families.

The Cancer Support Community is an international nonprofit organization that specializes in all things related to the cancer patient experience. Founded in 1982, the Cancer Support Community's mission is to ensure that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community. We deliver our free programs and services in 53 centers worldwide, online, and by phone through our National Cancer Support Helpline. We serve people with all cancers at any stage of disease, and their family members and loved ones.

We at CSC embrace the goals set forth by Vice President Biden. In particular, we are fully committed to the goal of doubling the rate of progress in the fight against cancer. And we challenge everyone here today to ensure that patients and their caregivers are your most trusted and steadfast confidantes and advisors throughout this process.

I think we can agree that one of the most effective ways to advance innovation for all patients is through participation in clinical trials. Yet today only 3-4 percent of eligible cancer patients participate in a clinical trial, and patient misperceptions remain the same as they have been since the 1970s – concern about being used as a 'guinea pig', receiving a placebo, and having to pay for care out of pocket. Trials today are in medical language – in clinical language – in legal language. Trials are overwhelming, intimidating and don't meet patients where they are. Misperceptions are negatively influencing patients' willingness to engage in the process. These misperceptions have to change if we are to see the kinds of advances that we all envision.

One of the themes of the Moonshot initiative is Collaboration. Just last week, the Cancer Support Community launched *Frankly Speaking About Cancer Clinical Trials*, a comprehensive, multi-media patient and caregiver educational program designed by patients, for patients to dispel the myths about clinical trials and to encourage patients to become active participants and partners in their care. This program was developed in collaboration with twenty organizations around the country who have worked tirelessly with us over the past year to develop and launch this innovative initiative.

Given what our research has shown, we felt it was important to take a fresh approach to this work. We began by talking with patients; hundreds of them from all across the US. We learned about their needs, their concerns and the barriers they face every day. We examined the emotional, personal, family, community and

cultural barriers to participation in trials, and are working **with** patients to find solutions. In fact, a lung cancer patient named Ide Mills, who is here today, and who spoke at our launch last week, was on 2 different clinical trials and said she would go on a third and a fourth and a fifth because she says a clinical trial saved her life.

The goals of the CSC clinical trials education program are simple: 1. Increase the level of awareness of and participation in clinical trials and, 2. Move decision-making to the patient. We want patients to be educated and empowered – to be smart and savvy decision-makers.

Frankly Speaking About Cancer Clinical Trials provides a comprehensive set of resources, powered by the full force of CSC's team of health professionals and our many partners, to deliver exactly what patients told us they need. This includes seeing and hearing about clinical trials from real people in their own words and having information about trials available at their fingertips; and the program reflects the desire by patients to have more time with their health care providers to better understand their options. I have no doubt that this program will positively impact the patient experience with and in clinical trials, and we are proud to make this available to our patients, your patients and the Cancer Moonshot Team.

We are witnessing unprecedented opportunities in cancer care delivery, where big data has allowed and will continue to allow researchers, doctors and nurses to treat patients with cellular level specificity. Yet we know from the voices of the patients we serve that attitudes and beliefs, coupled with data, drive behaviors and decisions. So, even in these most remarkable times, we **MUST** take the time to understand patients, to meet them where they are and to provide support and tools to empower them to be informed and engaged participants in their own care. Anything less will fall short of the goals we all hope to achieve on behalf of patients.

I want to close by sharing with you the unifying theme that emerged during our extensive work on this project – and that is **HOPE**. Hope that an individual patient will have access to better treatment and better quality of life, hope that future patients will benefit from those participating in trials today, and hope for a cure.

Hope is at the very heart of what drove Vice President Biden to launch the Cancer Moonshot. There are those that may try to diminish what Moonshot can accomplish, but we at the Cancer Support Community believe that hope, coupled with the commitment and expertise that surrounds this bold initiative, is at the core of innovation and promise for patients.

We at CSC look forward to working with you today and beyond to ensure patients remain at the center of Cancer Moonshot and that we indeed advance progress in both the medical and psychosocial aspects of the patient experience with cancer. Let's remember that patients are our True North in all that we do – let's ensure that the patient voice is heard – and that theme of hope drives our work today and well into the future.

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