



# Cancer Moonshot:

**ONE YEAR LATER**

JUNE 27, 2017 – WASHINGTON, DC

*To double the rate of progress in our understanding, prevention, diagnosis, treatment, and care of cancer.*



**CANCER SUPPORT  
COMMUNITY.**

*A Global Network of Education and Hope*

An event held by: the Cancer Support Community, American Cancer Society Cancer Action Network, CancerCare, Friends of Cancer Research, LIVESTRONG Foundation, National Coalition for Cancer Survivorship, and the National Patient Advocate Foundation.

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# About the Cancer Moonshot

In his final State of the Union address in January 2016, President Barack Obama turned to Vice President Joe Biden and requested on behalf of the nation that he lead a new venture—the “Cancer Moonshot.” Its vital mission would be to catalyze efforts that would achieve a decade’s worth of progress in preventing, diagnosing, and treating cancer, in just five years.

To transform this challenge into reality, President Obama created the Cancer Moonshot Task Force. He charged the group with leveraging federal resources and collaborating with the private sector and patient groups to achieve its mission.<sup>1</sup> Under Vice President Biden’s leadership, the Task Force convened over 20 federal government departments, agencies, and White House offices. Together, these partners developed five strategic goals and converted them into tangible achievements advancing the Moonshot’s bold mission.

Although built on existing scientific efforts, the Cancer Moonshot Task Force stressed that this would not be “business as usual.” The Task Force detailed three principles to guide all of their actions and recommendations. The Task Force would:

- drive innovation in the current cancer ecosystem by pursuing audacious, creative, and disruptive approaches.
- collaborate across disciplines, sectors, and borders to leverage talent and expertise.
- share information rapidly to drive advances and crowdsource solutions.

As part of its mandate, the Task Force was also directed to consult with a wide range of multidisciplinary experts, including the presidentially-appointed National Cancer Advisory Board (NCAB).<sup>2</sup> A Blue Ribbon Panel (the Panel) was formed that considered over 1,600 ideas submitted by the broader cancer community. Working together, the Panel assessed cross-cutting themes and distilled the most important ideas into ten transformative



## The Cancer Moonshot Strategic Goals

- Catalyze new scientific breakthroughs.
- Unleash the power of data.
- Accelerate bringing new patent therapies to patients.
- Strengthen prevention and diagnosis.
- Improve patient access and care.

<sup>1</sup> For the full Moonshot Task Force Report, visit [https://obamawhitehouse.archives.gov/sites/default/files/docs/final\\_cancer\\_moonshot\\_task\\_force\\_report\\_1.pdf](https://obamawhitehouse.archives.gov/sites/default/files/docs/final_cancer_moonshot_task_force_report_1.pdf).

<sup>2</sup> For more information on the NCAB, visit <https://deainfo.nci.nih.gov/advisory/ncab/ncab.htm>.

research recommendations to achieve the Cancer Moonshot's ambitious goals. The Panel report was submitted to the NCAB in September 2016.<sup>3</sup>

Even before the Panel Report was issued, however, it was clear that the Cancer Moonshot galvanized a national call to action. From the beginning, Vice President Biden and his team reached out to a wide range of individuals—basic and applied researchers, oncologists and other care providers, philanthropists, data and technology experts, patients and survivors, advocates, and representatives of private industry. During the June 29, 2016, Cancer Moonshot Summit at Howard University, Vice President Biden called on these and other stakeholders to unite as they envisioned ways to achieve a decade's worth of progress in half the time. Enthusiastically responding, the participants and outreach efforts helped to inspire over 300 local summits across the country that engaged over 7,000 individuals across all 50 states, sparking passionate discussions and generating numerous ideas. By the time its final report was issued, the Cancer Moonshot and its stakeholders announced 54 new private sector actions and collaborations, in addition to having initiated many new Federal efforts.

**In his final report to President Obama, Biden outlined five priorities to ensure that the Cancer Moonshot would continue to meet its strategic goals. These include:**

- realigning the incentives in the research system;
- enhancing prevention and screening efforts;
- engaging patients as partners in research;
- expanding access to care; and
- creating new financial models to improve the development of and access to new therapies while addressing the issue of rising drug prices.<sup>4</sup>

**One-year later on June 27, 2017, Cancer Moonshot partners convened to assess their accomplishments and understand what barriers they must continue to address.**

<sup>3</sup> For the full Blue Ribbon Panel report, visit <https://www.cancer.gov/research/key-initiatives/moonshot-cancer-initiative/blue-ribbon-panel#ui-id-2>.

<sup>4</sup> For Vice President Biden's 2016 Cancer Moonshot Report to President Obama Executive Summary, visit [https://obamawhitehouse.archives.gov/sites/default/files/docs/finalvp\\_exec\\_report\\_10-17-16final\\_3.pdf](https://obamawhitehouse.archives.gov/sites/default/files/docs/finalvp_exec_report_10-17-16final_3.pdf).

# Celebrating One Year of Progress: THE SUMMIT OVERVIEW

On June 27, 2017, seven leading cancer organizations including the Cancer Support Community (CSC), American Cancer Society Cancer Action Network (ACS CAN), CancerCare, Friends of Cancer Research, LIVESTRONG Foundation, National Coalition for Cancer Survivorship (NCCS), and National Patient Advocate Foundation (NPAF) convened to celebrate one year of progress toward achieving the mission and strategic goals of the Cancer Moonshot.

This summary report highlights key achievements of the Cancer Moonshot and discusses current challenges and future opportunities for collaboration and innovation.

# Opening remarks by Kim Thiboldeaux, CEO, Cancer Support Community

*Thiboldeaux thanked everyone for attending and shared the following remarks:*

“On January 12, 2016, in his final State of the Union address, President Barack Obama made a statement that galvanized millions of patients, providers, researchers, and advocates. He said, ‘For the loved ones we’ve all lost, for the family we can still save, let’s make America the country that cures cancer once and for all.’ Those words created a renewed sense of hope and purpose in communities that have been working tirelessly for decades to conquer this terrible disease. I can remember exactly where I was when he made this statement, and I bet you can too. In just a year and a half, the world of cancer care has gone through a seismic shift. In that speech, the President charged Vice President Joe Biden with making this new ‘Cancer Moonshot’ a reality.

“Since that time the Vice President has made it his mission to catalyze innovation, collaboration, and hope in a way we have never seen before. He has said that we must inject the urgency of now into this fight and over the past year, he has done just that. As you all know, the Vice President lost his son Beau to brain cancer in 2015. He has stated that the Moonshot is personal for him but that it’s also personal for nearly every American and millions around the world. Simply put, we all are impacted by this disease and for those of us in this room, we have made it our lives’ work to alleviate some of the suffering and despair felt by patients, survivors, and families.

“Speaking recently, Vice President Biden stated that patient advocacy organizations, like all of ours, give patients a sense of hope and that the single most important ingredient to someone facing a difficult diagnosis is hope. To the Vice President, the Moonshot represents ‘the notion that we can do anything. The spirit of possibilities is contagious.’ Not only are we standing at a moment of immense possibility—but we are also standing at a juncture of great uncertainty. On the one hand, we are seeing biomedical innovation and progress on a level never witnessed before. Breakthroughs like immunotherapy hold incredible promise—yet that promise is tenuous when our leaders threaten to drastically cut funding for our nation’s research infrastructure. With better treatment options for many individuals, cancer has become a chronic disease and the number of survivors is expected to increase to more than 20 million over the next decade. However, health care coverage, access, and affordability are threatened by disastrous policy proposals at both federal and state levels.

“Today’s event is not political and it is not partisan—it is everyone’s obligation to use their talent, passion, and knowledge to chip away at this disease that has caused immeasurable



KIM THIBOLDEAUX,  
CEO, Cancer Support Community

**“In just a year and a half, the world of cancer care has gone through a seismic shift.”**

**— Kim Thiboldeaux**

pain and suffering throughout the world. President Woodrow Wilson once said:

*‘You are not here merely to make a living. You are here in order to enable the world to live more amply, with greater vision, with a finer spirit of hope and achievement. You are here to enrich the world, and you impoverish yourself if you forget the errand.’*

“As patient advocates, providers, scientists, researchers, and individuals personally impacted by this disease, we have a responsibility to protect the patients who depend on us to voice their fears, champion their values, and stand up for their rights. Dr. Martin Luther King, Jr. stated, ‘of all the forms of inequality, injustice in health care is the most shocking and inhuman.’

“The progress of the Cancer Moonshot depends on the courage of everyone in this room to create a more—not less—equitable system, that meets the needs of all patients, regardless of race, ethnicity, gender, socioeconomic status, zip code, or any other characteristic that has historically proven to segregate us and leave certain communities behind. All patients deserve to realize their personal hopes—a chance to live another day, to be free from pain, to witness life’s milestones, to receive respect, or even to die with dignity.

“The Cancer Moonshot is bigger than any one person or organization. The Vice President has spoken of the need to change the culture of health care. He said, ‘We can do this but only if we come together and break down barriers.’ This is why we are proud to join with six cancer organizations dedicated to addressing the needs of patients: Cancer Support Community, American Cancer Society Cancer Action Network, CancerCare, Friends of Cancer Research, the National Coalition for Cancer Survivorship, the National Patient Advocate Foundation, the LIVESTRONG Foundation. We also thank each and every one of you who joined us here. We know you are all busy but your presence here is a testament to your commitment to the Moonshot and to the patients you serve.

“I would also like to thank our Sponsors: Genentech, Novartis, Takeda, GSK, Deloitte, and Michael J. Hennessey Associates. They believed in our vision to make today happen and we thank them for supporting us. We have a packed program today. We will hear updates from some of the 60 organizations that made Cancer Moonshot pledges last year. We will hear about the continued Moonshot mobilization within the government and the status of the Blue

Ribbon Panel recommendations. Today, we will evaluate our progress and determine if we are on target to making ten years’ worth of progress in five years. We will renew our commitment to this cause, and I hope—despite the incredible odds we are facing—we will all be reminded of the vital importance of this work.

“Before we get started, I have one last quote to leave you with. Author Anne Lamott said,

‘Hope begins in the dark, the stubborn hope that if you just show up and try to do the right thing, the dawn will come. You wait and watch and work: You don’t give up.’ Today is yet another day to work—but it is also a milestone that signifies our unyielding passion to care for patients and our ceaseless pursuit to end this disease.”

**“Today’s event is not political and it is not partisan—it is everyone’s obligation to use their talent, passion, and knowledge to chip away at this disease.”**

**— Kim Thiboldeaux**

# Keynote by Greg Simon, President, Biden Cancer Initiative

## Not Just Care, but Caring

For Greg Simon cancer is personal, and when it comes to his cancer treatment, he knows he was lucky. Simon received exceptional care from leading physicians who were only a taxi ride away in New York City. He had caring support from his friends, family, and health care team, who were crucial to his journey. Commenting on what may be a relatively uncommon yet fortunate experience, Simon noted that “we have to do so much to make this [experience] systematic, not an exception.”

In the weeks leading up to the Summit, Congress proposed a set of bills to reform the health care system. Referencing those bills, Simon said, “Before we get to cancer, let’s make sure we get to caring about everybody, not just the people with good jobs. A river of disdain is washing over the poor in this country, and that is a death sentence for people with cancer if they don’t have insurance.” He continued that curable cancers often go untreated “all because of this disdain for the poor, and the refusal of the richest nation in the history of the world to spend money helping people who are the working poor, pregnant women, children, or people in nursing homes.”

Simon received the call to lead the White House Cancer Moonshot while still receiving cancer treatment. “It is what I was meant to do,” he said.



GREG SIMON,  
*President, Biden Cancer Initiative*

## The Cancer Moonshot is Alive

The Cancer Moonshot aims to double the speed of progress in cancer with the idea that, “If we ask people to work together to do something they aren’t doing yet and give them extra money and an army of people like you to support them to be bold and ambitious, people will answer the call,” said Simon.

A positive yet disruptive force, the Cancer Moonshot asked leaders in 2016 to form new collaborations and “to look up from their powerpoints, phones, and their traditional ways of working to answer the question: how do we do a better job of touching patients now, and in a big way?” said Simon. With inspiration from former Vice President Joe and Dr. Jill Biden and a focus on supporting patients in their journey from prevention to survivorship, Simon urged leaders to think about cancer care differently and to have crazy ideas that may turn out to be brilliant. Only one year into the effort, the Cancer Moonshot has moved

**“The Moonshot is alive in and out of the government, with the Biden Cancer Initiative, and with you.”**

**— Greg Simon**

ahead quickly on many initiatives ranging from improving patient transportation and speeding clinical trials to sequencing genomes more rapidly than in the past.

Highlighting the crucial role of the partners, Simon said, “The Moonshot can only reflect the light of the people working with us.” He emphasized that private sector leaders are constantly asking what more they can do and that “Even inside the government, Moonshot initiatives are led by career government workers, are funded for two years, and are unlikely to be retracted even by the new Administration.” He continued, noting that whether cancer programs will continue in a “Moonshot way, where we don’t take 12 months to approve research is an open question. In cancer, we can make a difference, if we choose to.”

Simon closed with remarks about the Biden Cancer Initiative (BCI), former Vice President Biden and Dr. Jill Biden’s venture to continue the fight to make progress in cancer prevention, detection, treatment, and care that launched in June 2017.<sup>5</sup> Simon told the audience that the BCI aims to advance the Cancer Moonshot, including making clinical trials more patient-friendly and patient-oriented in their design, improving data and pathology standards, and making cancer care more affordable and accessible to all segments of society regardless of their economic status or zip code. BCI is designed to survey the landscape to find scalable solutions, generate hard discussions to resolve barriers, convene leaders to focus on cancer and learn from each other, and spread the knowledge gained.



GREG SIMON, *President, Biden Cancer Initiative*

<sup>5</sup> The Biden Cancer Initiative launched in July 2017. For more information visit <https://bidencancer.org/>.

# Caregiver Perspective by Chris Draft, Founder, President, and CEO, The Chris Draft Family Foundation

## Remember What You Knew Before You Knew Cancer

Former NFL star Chris Draft knows what it means to be a caregiver for a loved one with cancer. Draft's life changed when his soon-to-be wife Keasha, who was in excellent health, was diagnosed with stage IV lung cancer at the age of 37. After being thrust into a new world, Chris and Keasha had to quickly "understand a new language." He explained how physicians often communicate with patients through new and complex terms. Draft's advice to the medical community and cancer advocates was to "Remember what you knew before you knew cancer." He noted, "You can feel like you know nothing very quickly."

Draft knows he was fortunate to have a high level of education, access to quality physicians, and a support network. "Still it was difficult for me," he commented. "I was a linebacker. I was the guy who took and gave hits, and I had to watch my wife take hits as chemo kind of worked and kind of didn't work. I had to watch her find the joy in every day as she took the pain," Draft explained.

The couple continued to find joy as Keasha was undergoing treatments and married in November 2011. A month later, Keasha Monique Rutledge Draft died. Even with abundant access to resources, "the medicine must work, and it didn't," her husband told the Moonshot audience.

Before their marriage, the couple launched the Chris Draft Family Foundation.

"It was time for us to go out and take the battle back," Draft explained. The Foundation's mission aligns with the public's long held belief that the primary problem of lung cancer is that poor prognoses are simply accepted. Reducing lung cancer typically means preventing tobacco use, but Draft's Foundation operates on the premise that people need to care about lung cancer itself, not just tobacco, given that as many as 20 percent of lung cancer deaths in the U.S. occur among non-smokers.<sup>6</sup>



CHRIS DRAFT,  
Founder, President, and CEO,  
The Chris Draft Family Foundation

**"It was time for us to go out and take the battle back."**

**— Chris Draft**

<sup>6</sup> American Lung Association. "Why Non-smokers Sometimes Get Lung Cancer." <https://www.cancer.org/latest-news/why-lung-cancer-strikes-nonsmokers.html> (Accessed August 11, 2017).



CHRIS DRAFT, *Founder, President, and CEO, The Chris Draft Family Foundation*

To advance progress in lung cancer prevention and treatment, Draft and his Foundation’s leaders thought hard about missed opportunities to reduce deaths from the disease. In 2013, Draft and his team helped to launch the National Lung Cancer Screening Event to encourage veterans—a population with a high concentration of lung cancer and a relatively poor prognosis—to get screened for the disease. After learning about the Cancer Moonshot, Draft was invited to the White House where he presented his team’s idea about a larger effort to put more resources behind systematic early detection for veterans.<sup>7</sup>

“[The White House] bought in” said Draft, as he noted, “I’m excited because I got to be a part of what happens when you have leadership at the top who wants to make a difference and change the face of lung cancer.” Draft continued, “As long as we stay committed, I know things are going to be great.”

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<sup>7</sup> For more information about the Chris Draft Foundation’s initiative with veterans, visit [http://www.chrisdraftfamilyfoundation.org/tools/press/files/ATI\\_2538158\\_2\\_CDFF-NATIONAL-VETERANS-SCREENING-KICKOFF-PRESS-RELEASE.pdf](http://www.chrisdraftfamilyfoundation.org/tools/press/files/ATI_2538158_2_CDFF-NATIONAL-VETERANS-SCREENING-KICKOFF-PRESS-RELEASE.pdf).

# Blue Ribbon Panel Update

Elizabeth Jaffee, MD, Professor and Deputy Director for Translational Research, Sidney Kimmel Comprehensive Cancer Center, Blue Ribbon Panel Co-Chair

Douglas Lowy, MD, Acting Director, National Cancer Institute

*Dr. Lowy and Dr. Jaffee articulated the National Cancer Institute's role in the Cancer Moonshot and highlighted achievements emanating from the Blue Ribbon Panel (the Panel) recommendations.*

"The Moonshot occurred at the most opportune time in the history of cancer research," began Dr. Jaffee. Since declaring a war on cancer over 40 years ago, basic science has advanced astronomically, "but we needed the Moonshot to turn this information into real treatments affecting patients with cancer."

Aiming to better understand the full spectrum of cancer by improving cancer prevention, screening, treatment, and survivorship, the Panel's recommendations exemplify

the Moonshot's balanced approach to cancer. Thanks to the Moonshot, The National Cancer Institute (NCI) has an additional \$1.8 billion over the next seven years to focus on the Panel's recommendations while continuing research and training activities under its regular funding levels.

**"The Moonshot occurred at the most opportune time in the history of cancer research."**

**— Elizabeth Jaffee, MD**

## Blue Ribbon Panel Achievements

To develop Panel recommendations, the NCI collected comments from all interested parties, including patients, researchers, clinicians, advocates, and others. Remarkably, their basic priorities aligned.

Early in the Cancer Moonshot, Vice President Biden recognized the importance of data sharing, a priority that the Panel recommendations echoed. Specifically, the Panel recommended building a national cancer data ecosystem, beginning with a user-friendly data sharing platform to which patients, clinicians, and researchers could all contribute. Because of the Panel recommendations, the NCI is now collaborating with the Departments of Veterans Affairs (VA), Energy (DOE), and Defense (DOD) to build data-sharing technology for future use by scientific, advocacy, and patient communities.

Dr. Jaffee highlighted another Panel recommendation to develop a 3-D cancer atlas to integrate data concerning how different cells in cancer tumors communicate, allowing the cancer to grow and metabolize. Dr. Jaffee stated that "with a 3-D picture, we can start to figure out how to develop drugs that can inhibit or accelerate pathways leading to an anti-cancer response." She also explained how this information helps researchers better understand different cancer trajectories that may occur at different ages and in different ethnic groups. This is particularly important when trying to understand pediatric and young adult cancers. In the last year, the NCI has solicited applicants for its funding opportunity



ELIZABETH JAFFEE, MD  
Professor and Deputy Director  
for Translational Research,  
Sidney Kimmel Comprehensive  
Cancer Center, Blue Ribbon  
Panel Co-Chair

to advance the Atlas project, and in the spirit of the Cancer Moonshot, required applicants to demonstrate collaboration across different companies and organizations.

Dr. Lowy highlighted the important collaboration between the Gates Foundation and the NCI, which is trying to determine if a single dose of the vaccine against the human papillomavirus (HPV), a recognized cause of cervical and other cancers, can be as effective as the current three-dose regimen in conferring long-term protection. If proven possible, this Moonshot-funded effort will increase vaccine uptake in the U.S. and around the world, while “saving the American medical system millions in vaccine costs.” On the molecular side, Dr. Jaffee added that the NCI is enhancing programs to identify and target the genetic signature of preventable cancers that can be used to conduct targeted screening.

Finally, Dr. Lowy recognized the need to intensify pediatric cancer treatment research and the critical role of the NCI in doing so, given the relatively small patient population that limits the financial incentive for industry to be highly involved. He highlighted the recent NCI pediatric cancer research focus on curing cancers caused by rearranging genes—important but challenging research with potential implications for similar adult cancers.

## International Impact

Dr. Lowy noted that even when meeting with former Vice President Joe Biden to discuss other political agendas, leaders in other countries were asking about cancer. The NCI signed memorandums of understanding with a number of countries or international institutions. In addition, institutions from ten countries have self-assembled the International Cancer Proteogenome Consortium, catalyzed by the Cancer Moonshot.<sup>8</sup>

“When Greg [Simon] says the Moonshot is alive and well, it’s not just alive and well in the U.S. but also internationally,” Dr. Lowy told the assembled guests.

“...the Moonshot is alive and well...not just in the U.S. but internationally.”

— Douglas Lowy, MD

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<sup>8</sup> The International Cancer Proteogenome Consortium is a forum for collaboration among leading cancer and proteogenomic research centers in the world. Proteogenomics is an area of research at the interface of proteomics (the study of human proteins) and genomics (the study of the genome). For more information visit: <https://proteomics.cancer.gov/programs/international-cancer-proteogenome-consortium>.



## Panel Presentations and Discussions

During four panel sessions, panelists presented their organization's Cancer Moonshot pledge and progress toward meeting their goals, while discussing challenges and opportunities moving forward.





ALLEN, DEFRIAS, CAMPBELL, CHEN, HOOS, AND MCKEE

## Improving Cancer Clinical Trials

- Alicyn Campbell, MPH, Global Head, Patient-Centered Outcomes Research for Oncology, Genentech
- Alice Chen, MD, Early Clinical Trials Development Program, National Cancer Institute
- Kara DeFrias, Former Cancer Moonshot Experience Design Director
- Amy McKee, MD, Deputy Office Director (Acting), Office of Hematology and Oncology Products, U.S. Food and Drug Administration
- Axel Hoos, MD, PhD, Oncology Head, GlaxoSmithKline

*Moderator: Jeff Allen, PhD, President and CEO, Friends of Cancer Research*

*The Cancer Moonshot Task Force recognized that improving clinical trials systems and expanding access to disadvantaged populations are essential to advancing research and improving access to care. In this panel, speakers discussed how the Cancer Moonshot has propelled each organization and agency to expedite drug discovery and approval and has made clinical trials more patient-oriented and available to a greater diversity of patients to improve treatment outcomes.*

“Patients are rarely asked for first hand comprehensive information about what it’s like to undergo treatment or live with a disease...this represents a lost opportunity.”

— Alicyn Campbell, MPH, Global Head,  
Patient-Centered Outcomes Research  
for Oncology, Genentech

## Genentech: Capturing the Patient Experience in Global Clinical Trials

Genentech envisions a future where therapies include a patient-friendly label that communicates patient experiences in clinical trials. Currently, clinical trials inadequately capture patients’ first-hand experiences with cancer treatment and physicians underreport side effects by at least 50 percent. Therefore, information available about adverse side effects is insufficient to inform patient decision-making. As part of the Cancer Moonshot, Genentech is spearheading an industry working group to address barriers to using the Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE) in clinical trials. PRO-CTCAE is a publicly funded tool containing 124 items representing 78 toxicities on which patients can report.<sup>9</sup>

After identifying language translation as a key barrier to adopting PRO-CTCAE, Genentech’s team has nearly completed translating PRO-CTCAE into approximately 35 languages and will soon make the enhanced version of the tool available on NCI’s website. Genentech expects that global access to NCI’s PRO-CTCAE tool will dramatically accelerate the standardized collection of patient-reported data including side effects, which when communicated through patient-friendly labels, will better inform treatment decisions.

“[NCI-MATCH] is open to anyone with a solid tumor or myeloma, and they can have [the trial] done at home.”

— Alice Chen, MD, Early Clinical Trials  
Development Program,  
National Cancer Institute

## The National Cancer Institute: Bringing Precision Medicine Trials to Communities

With NCI-MATCH (Molecular Analysis for Therapy Choice), the NCI, in collaboration with pharmaceutical companies, opened a major precision medicine clinical trial in over 1,100 sites across all 50 states and in Puerto Rico and Washington D.C. If a patient’s gene mutation was targeted by an NCI-MATCH drug, the drug therapies were sent to their local treatment facility, allowing patients to receive treatment near their homes. Because NCI-MATCH screening does not require a specific histology but is open to anyone with a solid tumor or myeloma, the trial attracted a large number of rare tumor patients. With 60 percent of trial enrollees presenting with rare tumors, the trial significantly increased the genomic data pool for such tumors.

Interest in NCI-MATCH was so high that the NCI quickly doubled the number of participants to 6,000 and closed enrollment in half of the expected time. Using a central Institutional Review Board (IRB) allowed sites to avoid the lengthy process of obtaining individual IRB approvals, which was key to successfully opening 1,100 new sites in such a short time period.

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<sup>9</sup> PRO-CTCAE was created by the NCI to capture adverse symptoms in patients on cancer clinical trials. For more information visit <https://healthcaresdelivery.cancer.gov/pro-ctcae/> and <https://www.gene.com/stories/more-than-numbers>.

“At every point in our journey, the patient was at the center.”

— Kara DeFrias, Former  
Cancer Moonshot  
Experience Design  
Director

## The Obama White House Presidential Innovation Fellows: Connecting Clinical Trials to Patients

The White House Cancer Moonshot team and the NCI interviewed 200 patients, caregivers, doctors, advocates, and technology companies, identifying three deliverables to make clinical trials and data more accessible to patients.

First, the team created an Application Programming Interface to make the NCI clinical trials information database and search engine more easily accessible and to enable patients and advocates to better use the data for their own needs. After a usability test of NCI’s clinical trials database, the team increased the site’s use of plain English and reduced the number of initial search fields from 12 to 3, yielding greater usage of the website and enabling more users to find potentially matching trials. The Cancer Moonshot team also structured the data or altered the data’s format, so that investigators can use it more easily.

“The Oncology Center of Excellence aims to think of the patient as a whole—from diagnosis to treatment to survivorship. We want to help patients through the journey.”

— Amy McKee, MD, Deputy Office Director (Acting),  
Office of Hematology and Oncology Products,  
U.S. Food and Drug Administration

## The Food and Drug Administration: Expediting Drug Review and Increasing Access to Clinical Trials

The Food and Drug Administration (FDA) plays a critical role in facilitating the transition of products from discovery to market availability. With the Cancer Moonshot, the FDA committed to expediting oncology drug reviews, increasing enrollment, and incorporating the patient voice through multiple initiatives.

One FDA Cancer Moonshot initiative involved creating the Oncology Center of Excellence (OCE). The OCE’s mission is to achieve patient-centered regulatory decision-making through innovation and collaboration. By leveraging experts across the agency’s offices and centers, the OCE expedites the oncology drug review process. To date, the OCE has launched and is conducting product and marketing application reviews. In the long-term, the OCE plans to act on its driving principle that it should consider the whole patient and improve processes, programs, and initiatives that can aid patients through their cancer journey.

To enhance the diversity of clinical trial patients, the FDA also partnered with the American Society of Clinical Oncology and Friends of Cancer Research. Together they created working groups to broaden clinical trial eligibility criteria to include patients with organ dysfunction, brain metastases, HIV, and other conditions. Workgroup recommendations are being developed rapidly and the next step will be deciding how best to implement them.

Finally, the FDA aims to elevate the patient’s voice in clinical trials research. The agency has named multidisciplinary teams of social science researchers, statisticians, and disease specialists to better understand patient-reported data and eventually reflect such data on the drug label.

“There has not been a better time to work in cancer research... we are making more impact now than we ever have.

— Axel Hoos, MD, PhD,  
Oncology Head, GlaxoSmithKline

## GlaxoSmithKline: Collaborating to Accelerate Drug Discovery

GlaxoSmithKline (GSK) strives to advance oncology research and is involved in two major Cancer Moonshot initiatives. The ATOM (Accelerating Therapies for Opportunities in Medicine) project, is a collaboration between GSK, the National Cancer Institute (NCI), and the Department of Energy (DOE). It aims to combine the supercomputing capabilities of the DOE, the cancer expertise of the NCI, and the drug development expertise of GSK to accelerate drug discovery by ten times the current rate. Progress in the ATOM project has soared beyond the design phase, with all contracts signed, a new office in the San Francisco Bay Area established, and all partners actively engaged. In the next four years, GSK hopes the project will ease and increase the capture of electronic patient data, enhancing the data’s research potential while fostering more systematic studies to accelerate research.

The second initiative is the Partnership for Advancing Cancer Therapies (PACT)—a public-private partnership between the NCI, and at least 12 industry partners, foundations, and philanthropies that will focus part of its energy on finding unique solutions to accelerate progress in cancer clinical trials. Currently, PACT is dedicated to biomarker research and raising funds to support valuable clinical trials for combination therapy. Challenged with raising industry funds, the partnership has yet to start co-funding the combination therapy clinical trials.



# Challenges and Opportunities in Advancing Cancer Clinical Trials

During the panel discussion and audience questions, several challenges and future opportunities to advancing clinical trials were raised. Each is described below.

## Challenges to Advancing Clinical Trials

Barriers to data sharing continue to hamper the ability of researchers to advance clinical trials. Part of the challenge is translating unstructured clinical data to a sharable construct that multiple researchers across different trials and disciplines, and in different countries and settings, can use.

Significant gaps remain in pediatric and adolescent clinical trials.

Aligning the interests of so many diverse partners can be challenging. While former Vice President Joe Biden's inspirational leadership helped overcome this challenge in many instances, it remains difficult to raise joint funding, particularly from industry partners.

## Opportunities for Researchers, Advocates, Institutions, Government, and Policymakers

Encourage all stakeholders to participate in data sharing to facilitate and expedite increasingly complex cancer research.

Invest in and adopt technologies that can translate unstructured clinical data (i.e. doctors' notes).

Develop and implement policies to encourage drug development in younger patients, find ways to include younger patients in more trials where the pediatric and adult diseases are sufficiently similar, and extrapolate how data applies to younger patients.

Continue the momentum of the Cancer Moonshot beyond five years to mobilize funding, promote data sharing, and maintain and grow partnerships.



PUGACH, PUCKREIN, DOYKOS, SELBY, AND BELIVE

## Eliminating Disparities in Cancer

- Lauren Belive, Senior Federal Government Relations Manager, Lyft
- Patricia Mae Doykos, PhD, Director, Bristol-Myers Squibb Foundation
- Gary Puckrein, PhD, President and Chief Executive Officer, National Minority Quality Forum
- Joe Selby, MD, PhD, Executive Director, Patient Centered Outcomes Research Institute

*Moderator: David Pugach, JD, Vice President of Federal Relations, American Cancer Society Cancer Action Network*

*The 2016 Cancer Moonshot Taskforce called for increased access to cancer care. The Eliminating Disparities panel brought together four leaders across sectors who built upon their organizational and company strengths to engineer innovation and bring modern cancer care to vulnerable communities.*

“Universal transportation for cancer patients is our goal.”

— Lauren Belive, Senior Federal Government Relations Manager, Lyft

“Cancer excellence should require thinking about equity.”

— Patricia Mae Doykos, PhD, Director, Bristol-Myers Squibb Foundation

## Lyft: Bringing Transportation Innovation to Cancer Patients

Leaders at Lyft recognize that access to affordable and timely transportation is a major hurdle to cancer care among underserved and low-income populations. In Lyft’s commitment to the Cancer Moonshot, the company partnered with Boston Cancer Support to subsidize patients’ rides to medical appointments. Two major innovations for Lyft, as they developed this service, include a web-based alternative to their smartphone application, allowing patients without access to smartphones to participate, and a program allowing medical entities to call rides for their patients.

By 2020, Lyft hopes to offer free rides to cancer patients in the over 300 urban, suburban, and rural communities in which it operates. To accomplish this feat, Lyft must overcome challenges including providing more handicap accessible vehicles and addressing the high costs of transportation. Partnerships such as new collaborations with insurance giant Blue Cross Blue Shield and the clinical trials patient recruitment company Continuum Clinical are key to overcoming the financial hurdles to growth. Over the long-term, Lyft envisions that lower-cost self-driving cars will dominate their fleet, reducing the program’s cost.<sup>10,11</sup>

## Bristol-Myers Squibb Foundation: Making Sure No Patients Are Left Behind

Connecting with community partners to fill gaps in government resources and focusing on quality improvements are core elements in the Bristol-Myers Squibb Foundation’s (BMSF) approach to the Cancer Moonshot. BMSF is committed to ensuring that the most vulnerable populations with the least resources obtain the cancer care they need. To achieve this goal, BMSF pledged \$25 million in grants to Project ECHO (Expanding Capacity for Health Outcomes) in Cancer and to four survivorship grants. Project ECHO in Cancer strives to elevate the level of care possible in a community setting by linking academic and community-based cancer centers. Through survivorship grants to the American Cancer Society, the University of South Carolina, the West Virginia Cancer Institute, and in the Mississippi Delta, BMSF supports increased resources for patients and physicians in vulnerable communities with the goal of increasing surveillance and improving online and telephone resources, social services, and nurse navigation.

Recently, BMSF launched additional initiatives to support Cancer Moonshot goals. These include partnering with the Rapid Health Foundation to provide e-learning platforms for patients in lower-education populations and to support the Department of Veterans Affairs (VA)’s lung cancer screening program.

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<sup>10</sup> For more information visit <https://www.forbes.com/sites/brucejapsen/2017/05/10/lyft-and-blue-cross-partner-to-get-patients-rides-to-the-doctor/#3aa9f9423b9e>.

<sup>11</sup> For more information about Continuum Clinical visit <https://continuumclinical.com/lyft>.

“In many communities, patients are getting 1950s level cancer care. The most important thing we can do is collectively say that is not ok.”

— **Gary Puckrein, PhD, President and Chief Executive Officer, National Minority Quality Forum**

## National Minority Quality Forum: Changing the Face of Cancer at the Local Level through Access to Community Level Data

The National Minority Quality Forum (the Forum) applies their expertise in data collection to give patient advocacy groups access to community level cancer data. The Forum collects health data from all 38,000 U.S. zip codes. Using geographical information systems, it also creates downloadable heat maps displaying which communities suffer the greatest burden from each type of cancer. Inspired by the Cancer Moonshot, the Forum committed to creating these heat maps for 12 cancer types. One year later, maps for six cancer types are available online. “Understanding what is happening in the community is important to change the face of cancer at the local level,” said Puckrein.

The Forum’s Cancer Moonshot commitment continues through its work with the Cancer Diversity Working Group, a collaboration of multi-sector stakeholders including industry and patient advocacy groups. In this working group, the Forum will lead efforts to better understand different underserved communities and implement measures to improve the quality of care, screening, and clinical trials outreach available to meet their unique needs.

“Research questions need to be more patient-centric.”

— **Joe Selby, PhD, Executive Director, Patient Centered Outcomes Research Institute**

## Patient-Centered Outcomes Research Institute: Ensuring Research Data Reflects the Real World

The Patient-Centered Outcomes Research Institute (PCORI) drives research with the patient at the center and aims to advance improved patient access to clinical trials and data sharing in a way that fosters studying and learning from real world experiences. A strength of this effort comes through their Patient Centered Clinical Research Network (PCORnet). In partnership with researchers, these networks are led by patients to increase the availability of data on their shared medical conditions or disorders and to identify appropriate topics for research. Together with these networks, PCORI compiles routinely collected data from hospitals and physicians and makes these data available to researchers. In the end, PCORnet’s data more accurately reflects the U.S. patient population than most other research databanks that rely mainly on data from volunteers.

Inspired by the Cancer Moonshot challenge, PCORI funded a collaborative cancer research group. This collaborative effort uses PCORnet’s “real world” evidence to improve screening and diagnostic activity, precision cancer medicine, cancer survivorship, rural cancer care, and comparative effectiveness research in cancer.

# Challenges and Opportunities in Eliminating Cancer Disparities

During the panel discussion and audience questions, several challenges and future opportunities to eliminating cancer disparities were raised. Each are described below.

## Challenges to Eliminating Cancer Disparities

Locally available clinical trials and interventions often fail to match community cancer needs.

A variety of different government rules and regulations create barriers to providing adequate and innovative transportation assistance to cancer patients.

Current federal investments in health care are insufficient to provide 21st century cancer care to all Americans.

## Opportunities for Researchers, Advocates, Institutions, Government, and Policymakers

Consider hotspots for specific cancers when identifying locations for clinical trials and other interventions.

Establish systematic partnerships between rural hospitals and major cancer centers.

Amend rules and regulations that create barriers to providing transportation services so that companies such as Lyft and other innovative providers can develop and offer new ways to transport cancer patients to needed care.

Advocate for more federal investments in health care.



GALLAGHER, LEIMAN, FITZSIMONS, IBRAHIM, AND KELLEY

## Opportunities through Data Sharing

- Michael Fitzsimons, PhD, Genomic Data Commons User Services Manager, University of Chicago
- Ramy Ibrahim, MD, Vice President and Head of Research and Development, Parker Institute for Cancer Immunotherapy
- Michael J. Kelley, MD, National Program Director for Oncology, Specialty Care Services, Veterans Health Administration
- Lauren Leiman, Executive Director, BloodPAC

*Moderator: Kathleen Gallagher, MPH, Senior Director of Health Services Research and Outcomes, National Patient Advocate Foundation*

*In his one year report to President Obama, Vice President Biden recognized “[a] lack of open access and rapid sharing of research data and results allowing researchers to build on each other’s successes—and failures—to make new discoveries faster.” This panel highlights progress, as well as continued challenges and opportunities in data sharing.*

“If there was a way to standardize data use agreements, data sharing would be enabled on a much bigger scale.”

— Michael Fitzsimons, PhD,  
Genomic Data Commons User Services  
Manager, University of Chicago

## National Cancer Institute’s Genomic Data Commons: An Open Access System with Pre-Analyzed Big Data

Collecting, storing, and harmonizing data (unifying disparate data into a consistent, research-friendly format) are major challenges to data sharing. Rather than asking institutions to store massive amounts of data, the National Cancer Institute (NCI) built the Genomic Data Commons (GDC), a repository facilitating data sharing across multiple comparable projects by collecting data from many sources, harmonizing clinical data, and pre-analyzing the data to make it usable for the community.

As a part of the Cancer Moonshot, Foundation Medicine, which focuses on the innovative use of molecular testing to match each patient’s genomic profile to targeted therapies and clinical trials, followed through on its pledge to contribute data on 18,000 patients. Commercial cloud companies including Google and Amazon also fulfilled their pledges to donate resources, allowing the NCI to better store and analyze data for broader community use. Continued success hinges partly on the industry’s willingness to open their data and share it more widely. Maintaining the Cancer Moonshot’s energy and support over time is paramount in encouraging and strengthening data sharing.

“We need to do the leg work for scientists so they don’t spend time merging excel sheets.”

— Ramy Ibrahim, MD, Vice President and  
Head of Research and Development, Parker  
Institute for Cancer Immunotherapy

## Parker Institute for Cancer Immunotherapy: Removing Data Sharing Obstacles

The Parker Institute for Cancer Immunotherapy (PICI) is an organization committed to accelerating the development of breakthrough immunotherapies to turn cancer into a curable disease. PICI accomplishes this largely by removing data sharing obstacles and by promoting high-reward research. Armed with innovative data sharing systems, top researchers, and a team of mathematicians and engineers, PICI is targeting research and data pertaining to cancers they consider neglected by others such as advanced pancreatic cancer.

Beginning with six academic cancer centers, PICI is offering researchers the infrastructure to freely share data, knowledge, and discoveries. For example, PICI enables researchers to more easily share data by creating a system that will capture data in any format. PICI addresses other data sharing barriers by helping to manage varied intellectual property policies across institutions and by providing licensing support and shared research tools and infrastructure.

“With so many opportunities, staying focused on high reward projects is the challenge.”

— **Michael J. Kelley, MD, National Program Director for Oncology, Specialty Care Services, Veterans Health Administration**

“Now, [partners] love the opportunity to sit down quarterly, have a face to face meeting, and comb through the data together.”

— **Lauren Leiman, Executive Director, BloodPAC**

## The Veterans Health Administration: Using IBM’s Watson to Analyze Tumors and Advance Precision Oncology

Working with the Cancer Moonshot, the Veterans Health Administration (VHA) has pledged to collect and analyze gene panel data from all of their lung and prostate cancer patients. As a part of its precision oncology program, the VHA is collecting samples across their hospitals and partnering with IBM to use Watson Genomics to identify likely cancer-causing mutations and targeted treatment options. The VHA has already collected samples from 50 percent of their sites and has begun using Watson Genomics to interpret results.

The VHA’s efforts will not stop with this initial data collection. VHA systems are built to follow cancer patients over time, documenting their treatment regimens and outcomes. In addition to its essential partnership with IBM, the VHA formed a partnership with the DOE to ensure secure data storage and allow over 1,000 investigators to access the data simultaneously. Other non-profit and corporate partners will help the VHA more fully analyze the data and identify new research questions, extending the data’s ability to generate and answer new research questions.

An important component of the VHA’s research data is the diversity of the population that it represents. Because 35 percent of the VHA population is rural, unlike most researcher-oriented academic medical centers, this new VHA effort will help bridge rural-urban disparities in acquiring data and tailoring care to meet local needs.

## Blood Profiling Atlas in Cancer: Creating an Open Data Commons

A concept that was formed by the White House Cancer Moonshot Office, the Blood Profiling Atlas in Cancer (BloodPAC) aims to strengthen the ability of researchers to profile and assay blood (i.e., analyze blood for the presence or amount of a particular substance in the blood to help monitor and treat cancer). BloodPAC’s mandate is to accelerate the development and validation of blood profiling assays by aggregating data from partners in academia, government, biotechnology, and diagnostic companies; harmonizing the data and making it freely available.

To create BloodPAC, Vice President Biden brought together competitive partners and urged them to work together. Overcoming their initial skepticism, in the past year 35 members of this non-profit consortium organization have already contributed data to accelerate the use of liquid biopsies to better understand how a patient’s disease evolves over time.<sup>12</sup> BloodPAC envisions that in two years their products will be ready for clinical use. In the meantime, the consortium plans to educate both clinicians and patients about the benefits of using these assays and to ensure their widespread utilization, including in hard-to-reach populations.

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<sup>12</sup> A liquid biopsy is an alternative to a surgical biopsy, enabling doctors and researchers to gain information about the tumor through a blood test.

# Challenges and Opportunities in Advancing Data Sharing

During the panel discussion and audience questions, several challenges and future opportunities were raised. Each are described below.

## Challenges to Advancing Data Sharing

Insufficient sharing of electronic health record data across medical systems for patients treated at multiple medical centers hampers effectiveness and efficiency of health care.

Multiple individual complex data use agreements pose a burden to efficient data sharing.

Pharmaceutical companies, regulatory agencies, and institutions establish rules governing if and how patient data can be shared; however, patients have very little say.

Analyzing data quickly is challenging given the vast quantity of data coupled with an insufficient number of trained statisticians and data analysts who understand medical research.

## Opportunities for Researchers, Advocates, Institutions, Government, and Policymakers

Identify standards allowing medical data to be shared widely and openly across systems with minimal barriers to clinical use.

Standardize data use agreements to enable larger scale data sharing.

Advocate for changes across different institutional and clinical settings that will allow patients to decide if they wish to share their data.

Encourage statisticians and data analysts to gain extra training and pursue positions with health research applications.

Fund training programs in high-level data analysis and statistics.



RICHARDSON, SASLOW, MEAGHER, AND HUERTA

## Preventing Cancer

- Elmer Huerta, MD, MPH, Director, Cancer Preventorium, MedStar Washington Hospital Center - Washington Cancer Institute
- Beth Meagher, Federal Strategy Leader, Deloitte Consulting, LLP
- Debbie Saslow, PhD, Senior Director, Cancer Control Intervention for HPV Vaccination and Women's Cancer, American Cancer Society

*Moderator: Lisa Richardson, MD, MPH, Director, Division of Cancer Prevention and Control, Centers for Disease Control and Prevention*

*Recognizing that at least 50 percent of cancers can be prevented, the Cancer Moonshot listed strengthening cancer prevention and diagnosis as one of its five strategic goals. This panel discussed progress, challenges, and opportunities in preventing cancer, including the importance of disruptive communications and cost effectiveness.*

“A hospital should take care of their own neighborhood first.”

— Elmer Huerta, MD, MPH,  
Director, Cancer Preventorium,  
MedStar Washington Hospital Center,  
Washington Cancer Institute

“The XPRIZE...pushes the limits of what’s possible to change the world for the better.”

— Beth Meagher, Federal Strategy Leader,  
Deloitte Consulting

## Cancer Preventorium: A Cancer Institute Model for Community Engagement

The Cancer Preventorium in Washington D.C. provides the Hispanic/Latino D.C. community with a place to obtain preventive services regardless of language or insurance barriers. Currently, 97 percent of the Cancer Preventorium’s patients have health insurance, but many do not seek initial cancer screening until they have advanced stage cancers. Community education is essential to diagnosing cancer early.

In response to the community’s need, the Cancer Preventorium’s leadership launched “Colon Cancer Prevention in the Neighborhood,” a community education program that the Cancer Moonshot has recognized as an innovative effort to promote early and equitable screening. The American Cancer Society and Cigna Foundation funded the program that partners with D.C. council members, local community organizations, churches, and community health workers to educate every corner of the community about early colon cancer screening.

## Deloitte Consulting: Advancing Early Detection Through Incentivized Competition

Deloitte Consulting, LLP (Deloitte), a leading U.S. consulting firm, has committed to advancing Cancer Moonshot objectives through its collaboration with the XPRIZE Foundation. The XPRIZE is a “highly leveraged, incentivized prize competition that pushes the limits of what’s possible to change the world for the better... spurring innovation and accelerating the rate of positive change.”<sup>13</sup> Deloitte has a team of fellows dedicated to XPRIZE on a pro-bono basis to help “drive the design, experimentation, incubation, and rollout of new concepts, methods, and models of crowd-sourced incentivized prize competitions.”<sup>14</sup>

After meeting with cancer leaders and researchers, Deloitte decided to focus their XPRIZE fellows on early cancer detection using innovative and disruptive platforms. Specifically, Deloitte collaborated with the XPRIZE Foundation to create the Cancer XPRIZE, which challenges teams of individuals to develop innovative ways to accurately, rapidly, and affordably screen for early cancer. The team will launch the multi-phased XPRIZE in 2018. Because of the Cancer Moonshot’s emphasis on collaboration, Deloitte Consulting seized the opportunity to collaborate with the cancer community and remains committed to continued collaborations.

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<sup>13</sup> XPRIZE. “What Is an XPRIZE.” <http://www.xprize.org/about/what-is-an-xprize> (Accessed August 11, 2017).

<sup>14</sup> Deloitte. “The Deloitte and XPRIZE Strategic Alliance.” <https://www2.deloitte.com/us/en/pages/strategy/solutions/deloitte-xprize-foundation-strategic-alliance.html> (Accessed August 11, 2017).

“We need to find ways to make positive vaccine communication the norm.”

— Debbie Saslow, PhD, Senior Director, Cancer Control Intervention for HPV Vaccination and Women’s Cancer, American Cancer Society

## American Cancer Society: Disruptive Communication Advancing HPV Vaccination

The American Cancer Society’s (ACS) most visible Cancer Moonshot pledge was to double their annual research budget, currently at about \$100 million a year, over the next five years. Implementing cancer prevention is a top priority for ACS which supports, among other efforts, the National HPV Roundtable. Partnering with the Centers for Disease Control and Prevention (CDC), ACS created this coalition of public, private, and voluntary organizations and individuals dedicated to reducing the incidence of and mortality from HPV-associated cancers.

With support from the Cancer Moonshot, the HPV Roundtable was funded for an additional five years, allowing ACS to make long-term investments to implement a five-year social media and broader communications plan targeting providers and parents. With a long-term strategy to mobilize hundreds of ACS staff nationwide around the issue, the ACS expects to see major gains in HPV vaccination rates.



# Challenges and Opportunities for Preventing Cancer

During the panel discussion and audience questions, several challenges and future opportunities to preventing cancer were raised. Each are described below.

## Challenges to Preventing Cancer

Hospitals may not have the resources needed, or may be structured in such a way that they cannot fully engage their local communities. This makes it more difficult for hospitals to focus on improving community health more broadly.

The value of prevention is often unclear to consumers and policymakers.

Often, cancer prevention messages are ignored or not believed by the public.

## Opportunities for Researchers, Advocates, Institutions, Government, and Policymakers

Prioritize community cancer needs through hospital-led collaborations with influential community leaders and local voices to identify and implement education programs and other needed interventions.

Evaluate prevention programs regularly and demonstrate their return on investment to persuade consumers and policymakers to invest in prevention efforts, especially those involving behavioral change, new funding, and vaccine uptake.

Use trusted messengers, particularly those from outside of the cancer and public health communities. Also, use emerging new “disruptive communications” to communicate prevention messages more effectively and to increase the demand for early screening.



DR. IBRAHIM

## The Way Forward by Ramy Ibrahim, MD, Vice President and Head of Research and Development, Parker Institute for Cancer Immunotherapy

*In helping to conclude the conference, Dr. Ibrahim highlights how the Cancer Moonshot can inspire the private sector to boldly revamp the research process while launching a new generation of investigators that may—as Kim Thiboldeaux stated at the outset—bring an “unyielding passion to care for patients and our ceaseless pursuit to end this disease.”*

“What if the top cancer researchers were given the resources they need to pursue their boldest research?”

— Ramy Ibrahim, MD, Vice President and Head of Research and Development, Parker Institute for Cancer Immunotherapy

## The Parker Institute for Cancer Immunotherapy

In April 2016, Sean Parker, the founder of Napster and early Facebook executive, announced a 250 million dollar grant from the Parker Foundation to establish the Parker Institute for Cancer Immunotherapy (PICI). PICI’s vision mirrors Moonshot principles in its intention to be bold, disruptive, and to rapidly advance the science with new technology and improved collaborations.

Focusing on breakthroughs in immunotherapy, which harness the power of the immune system to target and destroy cancer, PICI’s model is based on giving the top researchers the resources they need to pursue bold research and on devising a unique approach to collaboration that can serve as model for cancer and many other diseases.

## PICI’s Approach: Find the Best Experts, Give Them Resources, Foster Collaboration

The PICI began by working with six leading immunotherapy scientists to head centers at top research institutions—MD Anderson, Memorial Sloan Kettering, University of California Los Angeles, University of California San Francisco, University of Pennsylvania, and Stanford University. By providing funding, PICI enables researchers to collaborate and spend fewer hours writing competitive grants. Unlike other funding streams, PICI wants to know the answers to scientific questions. If the study’s result is negative, researchers get funding to support their next idea.

The pillars of the approach are simple and straightforward: find the best experts, give them the infrastructure needed to achieve their goals most effectively, and promote the collaborations needed to develop bold and novel ideas. Coupled with creating data sharing infrastructure and collaboration platforms, PICI ensures data and study results are communicated rapidly. PICI’s computing tools allow scientists to gather, store, and analyze data in a way that allows partners to build rapidly upon each other’s research. Because PICI provides research institutions with lawyers and manages their intellectual property, researchers still have the patents to capitalize on their discoveries.

Key to PICI’s impact is the idea that “If we can save a few hours from the scientists’ days by doing things they would have otherwise had to do themselves, the

scientists can do more patient care and research,” said Ibrahim. By developing partnerships with pharmaceutical companies, PICI researchers no longer spend months forming individual agreements with industry. For clinical trials, PICI develops the infrastructure and manages the logistics, allowing PICI researchers to focus on developing their ideas and research protocols. Further, PICI streamlined the Institutional Review Board (IRB) process by creating a single IRB, saving researchers from across the institutions from acquiring six separate IRB approvals.

Finally, PICI recognizes that the newest generation of bright immunotherapy scientists may lack the resources to initiate their research. PICI established a fellowship program to fund young researchers and assist them in establishing their own research laboratories.



DR. IBRAHIM

## PICI's Results: Advancing Cancer Technology

PICI's collaboration now includes over 40 industry and non-profit partners, 4 clinical trials, 5 fellowships, and over 300 researchers in 60 labs. PICI has advanced promising new technologies. For example, PICI developed the Tumor neoantigen SeLECTION Alliance (TESLA) project, where 35 leaders from industry, non-profit, and academia have come together to advance exciting immune-based therapies that help to identify new cancer cell markers. These, in turn, can be used to target personalized therapies for individual cancer patients. PICI is also advancing T-cell cancer therapy, where scientists use the body's own T-cells, a special-type of white blood cell, to kill cancer cells. Finally, PICI has launched the first ever clinical trial using CRISPR, a new technology that allows scientists to edit the human genome and engineer longer lasting T-cells. The goal is to offer patients hope and a way forward—long-lasting treatments that will ultimately vanquish cancer.

# Summary of Opportunities for Researchers, Advocates, Institutions, Government, and Policymakers

Throughout their discussion, panelists identified 15 opportunities to further the Cancer Moonshot goals, each of which are listed below.

1. Continue the momentum of the Cancer Moonshot beyond five years to mobilize funding, promote data sharing, and maintain and grow partnerships.
2. Advocate for more federal investments in health care.
3. Identify standards allowing medical data to be shared widely and openly across systems with minimal barriers to clinical use.
4. Standardize data use agreements to enable larger scale data sharing.
5. Advocate for changes across different institutional and clinical settings that will allow patients to decide if they wish to share their data.
6. Amend rules and regulations that create barriers to providing transportation services so that transportation and ride-sharing companies can develop and offer new ways to transport cancer patients to needed care.
7. Encourage all stakeholders to participate in data sharing to facilitate and expedite increasingly complex cancer research.
8. Invest in and adopt technologies that can translate unstructured clinical data such as doctor's notes.
9. Encourage statisticians and data analysts to gain extra training and pursue positions with health research applications. Fund training programs in high-level data analysis and statistics.
10. Develop and implement policies to encourage drug development in younger patients, find ways to include younger patients in more trials where the pediatric and adult diseases are sufficiently similar, and extrapolate how data applies to younger patients.
11. Consider hotspots for specific cancers when identifying locations for clinical trials and other interventions.
12. Establish systematic partnerships between rural hospitals and major cancer centers.
13. Prioritize community cancer needs through hospital-led collaborations and with influential community leaders and local voices to identify and implement education programs and other needed interventions.
14. Evaluate prevention programs regularly and demonstrate their return on investment to successfully persuade individuals and policymakers to invest in prevention efforts, especially those involving behavioral change, new funding, and vaccine uptake.
15. Use trusted messengers, particularly those from outside of the cancer and public health communities. Also, use emerging new "disruptive communications" to communicate prevention messages more effectively.

## Partner Updates

Not all organizations who pledged to advance the cancer Moonshot presented at the Summit. The table below lists progress toward Cancer Moonshot commitments by 25 organizations.



## Alex's Lemonade Stand Foundation

<b>5-year Cancer Moonshot Vision &amp; Goals</b>	<ul style="list-style-type: none"><li>• Open a state-of-the-art bioinformatics lab and use 'big data' to advance the pace of childhood cancer research in the next 12-18 months</li><li>• Double the investment for childhood cancer research projects and family services to \$150 million in the next 5 years</li><li>• Objectively analyze existing science in the childhood cancer research community and look for patterns to share with scientists</li></ul>
<b>First Year Progress on Cancer Moonshot Commitment</b>	<ul style="list-style-type: none"><li>• Opened the Childhood Cancer Data Lab on August 1 and has completed the first round of initial hires</li><li>• Will reach \$150 million raised by the end of 2017</li></ul>
<b>Collaborating Organizations/Partners</b>	<ul style="list-style-type: none"><li>• Alex's Lemonade Stand Foundation is partnering with the Cancer Support Community</li></ul>

## Antidote

<b>5-year Cancer Moonshot Vision &amp; Goals</b>	<ul style="list-style-type: none"><li>• Include biomarker information, particularly mutation eligibility criteria into structuring work so that trial matching can happen at the mutation level</li><li>• Match patients to trials at the mutation level so that more patients can get involved with precision medicine and drive medical research forward</li></ul>
<b>First Year Progress on Cancer Moonshot Commitment</b>	<ul style="list-style-type: none"><li>• Developed a process to structure mutation eligibility and improve how patients are matched to trials at the mutation level— makes mutation information more accessible to patients and furthers enrollment in precision medicine</li><li>• Designed a domain-specific language to structure mutation criteria into a machine-readable format and mapped the language to the National Cancer Institute thesaurus</li><li>• Asked mutation-specific questions in the Antidote Match platform based on eligibility criteria in order to identify precision medicine trials for which patients are eligible to participate</li><li>• Launched Precision Medicine for Me with many other advocacy organizations and pharmaceutical companies</li></ul>

## Antidote (continued)

### Collaborating Organizations/Partners

- Antidote partnered with the National Cancer Institute, the White House, and organizations in Precision Medicine for Me: Patient Power, Patients Like Me, Bonnie J. Addario Lung Cancer Foundation, Free to Breathe, Lung Cancer Alliance, Lung Cancer Foundation of America, Patient Empowerment Foundation, SURVIVEit, Viviphi, LVNG with Lung Cancer, American Lung Association, CancerCare, Inspire, Inspire and American Lung Association Support Group, Lung Cancer Registry, National Comprehensive Cancer Network, National Cancer Institute Cancer Information Services

## Blood Profiling Atlas in Cancer (BloodPAC) Consortium

### 5-year Cancer Moonshot Vision & Goals

- Accelerate the exploration, implementation, and assessment of potential clinical utility of liquid biopsies with the aim to understand the temporal evolution of a patient's disease
- Aggregate and make accessible:
  - Data from CTC, ctDNA, proteins including tumor associated autoantibodies, and exosome assays. This also includes clinical data such as diagnosis, treatment history, and outcomes, as well as sample collection preparation and handling protocols
  - Clinical data such as diagnoses, treatment histories, and outcomes
  - Sample collection preparation and handling protocols
- Create a “patient disease and treatment path” so that the scientific and clinical communities have a better understanding of how a disease progresses and how to optimize choice of therapy at points in time

### First Year Progress on Cancer Moonshot Commitment

- Built BloodPAC Data Commons and is accepting data contribution from members
- Developing data model 2.0 to make the data publicly accessible by the end of 2017

### Collaborating Organizations/Partners

BloodPAC Consortium is partnering with Arkansas Bioinformatics Consortium (AR-BIC), AstraZeneca, Breast Cancer Research Foundation (BCRF), Celgene, College of American Pathologists, CytoLumina, Epic Sciences, Food and Drug Administration, Foundation Medicine, Genomic Health, Guardant Health, Memorial Sloan Kettering Cancer Center, Novartis, Open Commons Consortium, Personal Genome Diagnostics, Pfizer, Prostate Cancer Foundation, Provista, Seven Bridges, Sysmex Inostics, Thermo Fisher Scientific, University of Chicago Center for Data Intensive Science, University of Michigan research teams, Kuhn Laboratory at the University of Southern California, Dan Landau laboratory at Weill Cornell Medicine and the New York Genome Center

## Bristol-Myers Squibb Foundation

### 5-year Cancer Moonshot Vision & Goals

- Committed \$25 million in new funding to expand community-based resources along the cancer care continuum in high risk and medically underserved communities across the country
- Fund projects that aim to help patients overcome barriers to early detection, treatment, care, and access to the social support

### First Year Progress on Cancer Moonshot Commitment

- Awarded Project ECHO (Extension for Community Healthcare Outcomes) for CancerCare a 5-year \$10 million grant to enhance and expand delivery of cancer prevention, detection, and treatment/survivorship
- Implemented ECHO cancer clinics at the MD Anderson Cancer Center to support community-based primary care providers to deliver high quality cancer care in rural Texas
- Passed the ECHO Act with bipartisan support in Congress and enacted in December 2016
- Required the Department of Health and Human Services to study ECHO as a training and collaborative care model for rural communities
- \$750,000 was awarded to American Cancer Society, University of South Carolina College of Nursing, West Virginia University Cancer Institute, and the Mississippi Public Health Institute each to develop innovative Survivorship Care Models for lung cancer patients
- Two year \$200,000 grant was awarded to A Breath of Hope Lung Foundation to develop and implement an e-learning resource for lung cancer patients, families, and caregivers to promote better understanding of lung cancer management
- Three year \$5.8 million grant was awarded to VA-PALS Implementation Network to implement IELCAP lung cancer patient management protocols and programs at 10 VA Medical Centers nationwide that do not have active lung cancer screening programs

### Collaborating Organizations/Partners

Bristol-Myers Squibb Foundation is partnering with pharmaceutical companies, business development companies, biotechnology organizations, and academia

## CANCER101

### 5-year Cancer Moonshot Vision & Goals

- Expand the reach of Prescription to Learn (P2L) which is an interactive platform to curate resources and solutions to issues that patients and caregivers face in navigating health information to make informed decisions
- P2L will launch online in 4 tumor types to allow patients/caregivers to personalize their search for information and support, access resources aligned with learning style preferences, and view resource ratings from other patients, caregivers, and clinicians
- Expand additional cancer-specific curriculums that P2L that will be integrated into medical education curriculums for clinicians nationally
- Empower, inform, and engage patients to take control over diagnoses and partner with healthcare teams to make personalized medical decisions

### First Year Progress on Cancer Moonshot Commitment

- Launched P2L in 8 tumor types and has been integrated into a medical education curriculum to encourage clinicians to prescribe resources to patients/caregivers
- Developed Meaningful Partnership Continuum (MPC) to map the various phases of educating/engaging the patient and caregiver, provide consistent definitions across the continuum, provide a standard to measure the impact of patient education interventions, and facilitate partnerships between patients and their caregivers
- Tagged resources in P2L with a phase in MPC that allow better understanding of the information/support seeking pattern
- Expanded P2L to over 1200 hospitals and community practices nationwide
- Continued working on a platform to map solution services/tools to issues identified by patients and caregivers

### Collaborating Organizations/Partners

CANCER101 is partnering with the University of Texas MD Anderson Cancer Center, H. Lee Moffitt Cancer Center and Research Institute, Perlmutter Cancer Center at New York University Langone, and Mayo Clinic

## Cancer Support Community

### 5-year Cancer Moonshot Vision & Goals

- Launched the *Frankly Speaking About Cancer Clinical Trials* program, which is devoted to dispelling common myths and building awareness among patients and caregivers about the importance of clinical trials as an option
- The robust research and conversation has helped to inform the program through the eyes of the patient, and this will be rolled out to reach 500,000 patients in 2016

## First Year Progress on Cancer Moonshot Commitment

- Reached over 525,000 people since June 2016
- Distributed over 13,500 Photo Narratives and Fact Sheets (available in print, PDF, and eBook formats)
- Offered 15 in-person Clinical Trial workshops in 13 US states and Canada in 2016 and scheduled 27 in-person clinical trials workshops in 2017 in 20 US states and Canada
- 97% of participants would recommend the program to others, and more than 90% of the participants left the workshop feeling more confident in participating in treatment decisions, asking their doctor about and looking for potential clinical trials, and understanding how clinical trials work
- Began focus group research with Spanish speakers in Miami, Arizona, and NYC to create a Spanish cultural adaptation of Photo Narrative materials
- Presented a poster at the 2016 San Antonio Breast Cancer Symposium that highlighted results for breast cancer patients who responded to our survey
- Published “In Their Own Words” clinical trials patients and researcher testimonials
- Hosted a three webinar series that took place in September and October 2016
- Highlighted clinical trials from a patient perspective in a series of *Frankly Speaking About Cancer* internet radio shows in September and January
- Provided clinical trials navigation support on CSC’s Cancer Support Helpline
- Won a 2016 Digital Health Aware and a 2017 Bronze Anvil Award of Commendation

## Collaborating Organizations/Partners

Amgen, Astellas, AstraZeneca, Celgene, Karyopharm, Novartis, Pfizer, Takeda, BioMarin, American Cancer Society Cancer Action Network, Inc., American Institutes for Research, Association of Community Cancer Centers, BreastCancerTrials.org, Cancer Treatment Centers of America, Cancer Support Community Greater St. Louis, Council for Affordable Health Coverage, Friends of Cancer Research, In My Sister’s Care, National Patient Advocate Foundation, Oncology Nursing Society, Personalized Medicine Coalition, Susan Love Research Foundation, and Wisconsin Cancer Council

## Celgene

## 5-year Cancer Moonshot Vision & Goals

- Establish Standing in the Gaap Initiative to raise awareness of multiple myeloma in the African American community, increase diagnosis, and support those in getting proper care
- Focus on quality improvement
- Continue the efforts of the Cancer Moonshot Diverse Communities Working Groups to better understand and increase diversity in cancer clinical research and help clinicians increase cancer screening, prevention counseling, and specialist referral in minority and poor communities

## Celgene (continued)

### First Year Progress on Cancer Moonshot Commitment

- Established 4 key sub teams: Cancer Index, Patient & Community Engagement, Clinical Research, and Physician/Quality Improvement
- Produced several publications and defined important quality improvement measures and other key metrics
- Had the largest Multiple Myeloma presence on social media which has promoted the goal to increase awareness and support

### Collaborating Organizations/Partners

Celgene Corp is partnering with the International Myeloma Foundation, Multiple Myeloma Research Foundation, National Association for the Advancement of Colored People, and Congressional Black Caucus, pharmaceutical industry partners, American Society of Clinical Oncology Disparities Committee and Professional Societies

## Deloitte

### 5-year Cancer Moonshot Vision & Goals

- Provide the funding and create a technical team or scientific advisory board to design the Global Cancer XPRIZE design concept in partnership with XPRIZE Visioneers
- Activate the global cancer ecosystem to develop rapid, accurate, and affordable solutions to detect cancers early
- Develop and launch a platform that will amplify collaboration

### First Year Progress on Cancer Moonshot Commitment

- Continued working with XPRIZE to serve as a connector and liaison to recruit and secure prize funding through sponsorship and donor management by developing promotional materials for communicating the value of Global Cancer XPRIZE
- Developing investment and funding strategies to attract those commitments in the cancer ecosystem
- Strengthen the prize design to help activate the crowd globally to participate in accelerator prizes, provide seed funding through the competition, and encourage collaboration within competing teams
- Team will begin competing in the Cancer XPRIZE competition in early 2018 over the next four years

### Collaborating Organizations/Partners

Deloitte is partnering with Global Cancer XPRIZE team

## Family Reach

### 5-year Cancer Moonshot Vision & Goals

- Establish the Financial Treatment Initiative, a series of projects that seek to reduce cancer related financial toxicity by providing financial education, navigation, planning, and assistance to patients
- Implement a pilot project at Tufts Cancer Center in Boston, MA to reduce the medical and non-medical out-of-pocket costs associated with cancer treatment
- Work with national financial planning organizations (e.g. Foundation for Financial Planning, Financial Planning Association) to provide coaching services to cancer patients and their families
- Collaborate on parallel research efforts of the financial toxicity of cancer led by Dr. Veena Shankaran at the Fred Hutchinson Cancer Center in Seattle, WA funded by Safeway Foundation
- Provide preliminary data for larger studies and practical information to directly impact the quality of healthcare services in cancer centers

### First Year Progress on Cancer Moonshot Commitment

- Developed protocols and materials for the pilot projects at Tufts Cancer Center in Boston and Fred Hutchinson Cancer Center in Seattle—enrollment begins in October 2017 with Family Reach enrolling 20 adult cancer patients and 20 pediatric cancer patients in the Boston pilot, and Fred Hutchinson Cancer Center is enrolling 30 adult cancer patients
- Offered patients and their families the core component of the interventions (i.e. financial education, navigation, planning, and assistance)
- Measured participation, financial toxicity, and adherence to the treatment at enrollment, 3 months, and 6 months
- Collaborated with cancer centers to develop financial interventions that are relevant to their patients and feasible to implement in their setting

### Collaborating Organizations/Partners

Family Reach is partnering with Consumer Education and Training Services, Patient Advocate Foundation, NaVectis Group, Foundation for Financial Planning, Financial Planning Association

## Foundation Medicine

### 5-year Cancer Moonshot Vision & Goals

- Share data to fuel cancer research and precision treatments
- Drive research to find innovative therapies for pediatric cancers
- Share information and accelerate research efforts

## Foundation (continued)

### First Year Progress on Cancer Moonshot Commitment

- Contributed the genomic information for 18,000 adult solid tumor clinical cases into the NCI Genomic Data Commons (GDC) database
- Doubled the size of the GDC and Foundation Medicine became the first commercial entity to contribute genomics data to the National Cancer Institute in March 2016
- Released a portfolio in 2016 of pediatric cancer genomics and clinical samples to researchers across the globe to accelerate research within the global oncology community
- Contributed liquid biopsy data to the Blood Profiling Atlas (BloodPAC) along with 20 other stakeholders

### Collaborating Organizations/Partners

Foundation Medicine is partnering with providers, pharmaceutical and technology companies, and payers

## Genentech

### 5-year Cancer Moonshot Vision & Goals

- Accelerate progress in collection of patient reported data of known symptomatic side effects over the course of therapy
- Translate a standardized patient-reported side effect library (The National Cancer Institute's Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events, or PRO-CTCAE) into 14 languages for use across 16 countries
- Lead a collaborative industry work group to address the barriers to including PRO-CTCAE in clinical trials
- Ensure that patients around the globe have access to rigorous and reliable patient-reported evidence to guide treatment decision

### First Year Progress on Cancer Moonshot Commitment

- Worked with National Cancer Institute, linguistic validation experts, and patients to develop a rigorous process to translate the patient-reported side effect library and follow industry accepted criteria
- Incorporated feedback from patients of different ages, gender, and treatment regimens to reflect the patients' preferred terminology
- Translated the repository into 14 languages for free dissemination to researchers

### Collaborating Organizations/Partners

Genentech is partnering with National Cancer Institute, patient advocacy organizations, patients, and other pharmaceutical companies

## Partnership for Accelerating Cancer Therapies (PACT)

<p><b>5-year Cancer Moonshot Vision &amp; Goals</b></p>	<ul style="list-style-type: none"> <li>• Collaboration between the NIH and 12 biopharmaceutical companies, multiple research foundations, philanthropies, and the Foundation for the NIH, to fund pre-competitive cancer research and share broadly all data generated for further research, ultimately bringing more new therapies to patients in less time</li> <li>• Understand responses to cancer therapies, clinical trial platforms for combination therapies, predictive modeling approaches, and therapies for rare cancers</li> </ul>
<p><b>First year progress on Cancer Moonshot commitment</b></p>	<ul style="list-style-type: none"> <li>• Began raising funds for the PACT by the industry partners; with sufficient funds, the program will be established</li> </ul>
<p><b>Collaborating Organizations/Partners</b></p>	<p>PACT is partnering with Amgen, AstraZeneca, Bayer, Boehringer Ingelheim, EMD Serono, Genentech, GlaxoSmithKline, National Cancer Institute, Foundation for the National Institute of Health, Food and Drug Administration, Abbvie, Bristol Myers Squibb Foundation, Lilly Oncology, Pharmaceutical Research and Manufacturers of America, Takeda, Pfizer, Merck, and Novartis</p>

## LiveSTRONG Foundation

<p><b>5-year Cancer Moonshot Vision &amp; Goals</b></p>	<ul style="list-style-type: none"> <li>• Reach the milestone of serving 100,000 cancer survivors, which would double the number served to-date</li> <li>• Integrate the program into clinical practice across the country</li> <li>• Increase access to evidence based services for cancer survivors to reclaim health and well-being following a diagnosis</li> </ul>
<p><b>First Year Progress on Cancer Moonshot Commitment</b></p>	<ul style="list-style-type: none"> <li>• Served almost 12,000 cancer survivors nationwide, reaching a cumulative total of 50,257 since the program was created</li> <li>• Expanded of the program into new communities and support for the YMCAs to boost class enrollment</li> <li>• Built evidence to support the impact and return on investment of the program so that steps towards clinical integration can be taken</li> </ul>
<p><b>Collaborating Organizations/Partners</b></p>	<p>LiveSTRONG Foundation is partnering with the YMCA of the USA</p>

## Lyft

<b>5-year Cancer Moonshot Vision &amp; Goals</b>	<ul style="list-style-type: none"><li>• Expand its Boston-based “Treatment Transport” partnership to at least 94% of the US population that Lyft currently serves by 2020</li><li>• Significantly improve patient access to reliable transportation and address a critical challenge many patients and their families face while receiving cancer treatment</li></ul>
<b>First Year Progress on Cancer Moonshot Commitment</b>	<ul style="list-style-type: none"><li>• Achieved adoption across all healthcare partners who can now leverage Lyft to assist with patients getting to/from their appointments, regardless if a patient has the financial or technological means to order a Lyft themselves</li></ul>
<b>Collaborating Organizations/Partners</b>	Lyft is partnering with American Cancer Society, Ascension Health, Boston Cancer Support, Cancer Support Community, and Sutter Physician Services

## METAvivor Research and Support

<b>5-year Cancer Moonshot Vision &amp; Goals</b>	<ul style="list-style-type: none"><li>• Award \$1 million in scientific research grants focused on benefitting the already metastasized breast cancer patient in 2017</li><li>• Award \$2 million in scientific research grants focused on benefitting the already metastasized breast cancer patients in 2018</li></ul>
<b>First Year Progress on Cancer Moonshot Commitment</b>	<ul style="list-style-type: none"><li>• Raised \$1 million in 2017 and a Request for Proposals was circulated in research circles in February through March where around 200,000 Letters of Intent were received and almost 200 were invited to submit full proposals</li><li>• Raised close to \$750,000 of \$2 million commitment for 2018</li><li>• Spoke at Capitol Hill annually with stage IV patients of all cancer types and metastasis researchers with legislators of 40+ states to stress the need for more patient orientated research</li><li>• Aided in obtaining signatures for initiatives such as asking the National Cancer Institute to clarify their stage IV focused research program</li></ul>
<b>Collaborating Organizations/Partners</b>	METAvivor is partnering with the Metastasis Research Society

## National Alliance for Caregiving

<p><b>5-year Cancer Moonshot Vision &amp; Goals</b></p>	<ul style="list-style-type: none"> <li>• Examine the role of the family caregiver in clinical settings, which may inform drug development</li> <li>• Work to eliminate disparities in care and support for families who are managing cancer</li> </ul>
<p><b>First year progress on Cancer Moonshot commitment</b></p>	<ul style="list-style-type: none"> <li>• Released a national white paper on cancer caregiving with the Cancer Support Community and Dr. Erin Kent of National Cancer Institute in 2016</li> <li>• Continued caregiving research</li> <li>• Discussed new work on end-of-life caregiving with the American Cancer Society and Dr. Maggie Longacre of Arcadia University</li> </ul>
<p><b>Collaborating Organizations/Partners</b></p>	<p>National Alliance for Caregiving is partnering with the Cancer Support Community, American Cancer Society, NCI, Arcadia University</p>

## National Cancer Institute

<p><b>5-year Cancer Moonshot Vision &amp; Goals</b></p>	<ul style="list-style-type: none"> <li>• Improve the way that information about cancer clinical trials is made available to and accessible by the public</li> <li>• Increase the accessibility and availability of NCI-supported clinical trials to the public, primarily to patients, their families, and oncologists</li> </ul>
<p><b>First Year Progress on Cancer Moonshot Commitment</b></p>	<ul style="list-style-type: none"> <li>• Made NCI-supported cancer clinical trials available through an application programming interface (API) thereby allowing patients and oncologists to find information and learn about clinical trials by creating a clinical trial search tool accessible at <a href="https://cancer.gov/syndication/api">cancer.gov/syndication/api</a></li> <li>• Provided the cancer community with a tool to build applications, integrations, search tools, and digital platforms to bring clinical trial information to more patients, families, and providers</li> </ul>
<p><b>Collaborating Organizations/Partners</b></p>	<p>National Cancer Institute is collaborating with federal government staff including Presidential Innovation Fellows, the cancer research advocacy community, academia, and private industry</p>

## National Cancer Institute Blue Ribbon Panel

<p><b>5-year Cancer Moonshot Vision &amp; Goals</b></p>	<ul style="list-style-type: none"> <li>• Consult with external experts from relevant sectors to identify areas of cancer research that are poised for acceleration and will spur progress in preventing, diagnosing, and treating cancer in 5 years</li> <li>• Provide funding opportunities for the recommended areas of cancer research</li> </ul>
<p><b>First Year Progress on Cancer Moonshot Commitment</b></p>	<ul style="list-style-type: none"> <li>• Identified and published major topic areas/recommendations in April 2016 with 30 scientific experts, and reviewed more than 1600 new ideas from the broader cancer community</li> <li>• Established Cancer Moonshot Implementation Teams for each recommendation</li> <li>• Released funding opportunity announcements (FOAs) that align with the recommendation that can be supported with existing funds or 21st Century Cures Funding</li> </ul>
<p><b>Collaborating Organizations/Partners</b></p>	<p>The Blue Ribbon Panel partnered with nearly 30 cancer research experts from across the country, and also featured additional experts, including research advocates and NCI staff</p>

## National Cancer Institute—Children’s Oncology Pediatric Match

<p><b>5-year Cancer Moonshot Vision &amp; Goals</b></p>	<ul style="list-style-type: none"> <li>• Improve the development of new therapies and expand approaches to treat childhood cancer</li> <li>• Determine whether treating cancer in children/adolescents is effective by targeting certain genetic changes in tumors with specific targeted drugs</li> </ul>
<p><b>First Year Progress on Cancer Moonshot Commitment</b></p>	<ul style="list-style-type: none"> <li>• Activated Pediatric MATCH, a precision medicine trial for pediatric cancers, in July 2017</li> <li>• Implemented at around 200 sites nationwide and available to children and adolescents ages 1 to 21</li> <li>• Launched the trial with 7 treatment arms and will add new arms as drugs become available</li> </ul>
<p><b>Collaborating Organizations/Partners</b></p>	<p>Pediatric MATCH was developed and will be led jointly by the NCI and COG, part of the NCI-sponsored National Clinical Trials Network. NCI and COG has collaborated with various pharmaceutical companies to secure the agents being studied</p>

## National Cancer Institute Formulary

<p><b>5-year Cancer Moonshot Vision &amp; Goals</b></p>	<ul style="list-style-type: none"> <li>• Expand collaboration between government and private industry in cancer research</li> <li>• Improve efficiency of developing and delivering cancer therapies to patients</li> <li>• Provide researchers faster access to approved and investigational agents to improve preclinical studies and clinical trial implementation</li> </ul>
<p><b>First Year Progress on Cancer Moonshot Commitment</b></p>	<ul style="list-style-type: none"> <li>• Launched in January 2017 and is a public/private partnership between the NIH and major pharmaceutical and biotechnology companies</li> <li>• Allowed NCI to act as intermediary between investigators and participating companies, which has helped to streamline the access to agents with the potential to efficiently help more patients quickly</li> <li>• Expanded to include 27 agents from 7 companies which was double the agents available at the Moonshot launch in 2016</li> </ul>
<p><b>Collaborating Organizations/Partners</b></p>	<p>National Cancer Institute Formulary is partnering with multiple pharmaceutical companies, including AstraZeneca, Bristol-Meyers Squibb, Eli Lilly and Company, Genentech, Kyowa Hakko Kirin, Loxo Oncology, and Xcovery Holding Company LLC</p>

## National Minority Quality Forum and Sustainable Healthy Community

<p><b>5-year Cancer Moonshot Vision &amp; Goals</b></p>	<ul style="list-style-type: none"> <li>• Establish a minimum of 10 cancer indices</li> <li>• Convene a Cancer Diverse Communities Working Group to promote equity in cancer care and research</li> <li>• Greater enrollment of minorities in precision medicine research and through the maps promote early screening in communities and states</li> </ul>
<p><b>First Year Progress on Cancer Moonshot Commitment</b></p>	<ul style="list-style-type: none"> <li>• Published 5 cancer index maps to date</li> <li>• Established the Cancer Diverse Communities Working Group with medical societies, experts, patient groups, and drug developers</li> <li>• Hosted 2 meetings of the Cancer Diverse Communities Working Group, who have begun to develop projects that promote equity, including review of inclusion of minorities in cancer research, literature reviews, focus groups on optimal methods for outreach to minority and underserved communities, and implementation of QI and community engagement activities</li> </ul>

## National Minority Quality Forum and Sustainable Healthy Community, LLC (continued)

### Collaborating Organizations/Partners

National Minority Quality Forum and Sustainable Health Community, LLC is partnering with American Cancer Society, American Society of Clinical Oncology, CancerCare, Wake Forest University, Bristol-Myers Squibb, Merck, Amgen, Genentech, Takeda, Kentucky LEADS, Horizon BCBS

## Oncology Nursing Society

### 5-year Cancer Moonshot Vision & Goals

- Leverage the ONS Oncology Qualified Clinical Data Registry (Oncology QCDR) to better translate the science and decrease the amount of time it takes to bring about practice change for health professionals caring for patients with cancer
- Create demonstration projects that leverage the data exchange, involving the Oncology QCDR and other data sources, to show the patient outcome and financial impact of nurses in new models of care
- Conduct a practice improvement initiative in which selected clinical sites have the opportunity to engage with ONS to implement practice improvement initiatives that would enable participants to view quality measure data, and drive practice and quality improvement

### First Year Progress on Cancer Moonshot Commitment

- Developed and distributed documentation standards
- Engaged in one demonstration project involving the ONS Oncology QCDR within clinical settings
- Conducted a nursing research think tank to identify key areas of nursing research that will accelerate progress

### Collaborating Organizations/Partners

Oncology Nursing Society is partnering with Premiere Health and CancerLinQ

## Parker Institute for Cancer Immunotherapy

### 5-year Cancer Moonshot Vision & Goals

- Bring together the top minds in cancer immunotherapy research and support/fund the ideas that will lead to breakthrough discoveries
- Give researchers the most innovative tools and resources to fuel their discoveries
- Accelerate the development of breakthrough immunotherapies to turn cancer into a curable disease

<p><b>First Year Progress on Cancer Moonshot Commitment</b></p>	<ul style="list-style-type: none"> <li>• Launched high-risk, high-reward clinical trials and research studies to make the biggest impact</li> <li>• Streamlined the review process for faster approval of multicenter clinical trials to save both money and time</li> <li>• Collaborated closely with a network of researchers to help them get the most out of the data</li> <li>• Began training and supporting the next generation of scientific leaders in cancer immunotherapy and help fuel their research discoveries</li> <li>• Gave investigators access to cutting-edge technology and machines to ensure that they have the tools they need to facilitate and further progress research</li> </ul>
<p><b>Collaborating Organizations/Partners</b></p>	<p>Parker Institute for Cancer Immunotherapy is partnering with the top researchers in the country, leading industry and nonprofit partners, including disease-specific foundations and the Cancer Research Institute, as well as the Partnership to Accelerate Cancer Therapies to accelerate progress in cancer research</p>

**Project Data Sphere**

<p><b>5-year Cancer Moonshot Vision &amp; Goals</b></p>	<ul style="list-style-type: none"> <li>• Commitment towards data sharing and supporting the development of new tools to leverage collaborative research</li> <li>• Develop more innovative and effective treatment therapies</li> </ul>
<p><b>First Year Progress on Cancer Moonshot Commitment</b></p>	<ul style="list-style-type: none"> <li>• Added 30 more datasets that represent almost 20,000 patient lives from the National Cancer Institute's National Cancer Trials Network (NCTN) archive to the Project Data Sphere platform, which is found at <a href="http://www.projectdatasphere.org">www.projectdatasphere.org</a></li> <li>• Allowed researchers to have a single place to investigate cancer trials that span multiple sources</li> <li>• Simplified and accelerated the research process. The FDA Oncology Center of Excellence highlights the continued work to lead efforts in access to data and enable improved research and clinical outcomes</li> <li>• Collaborated with the National Cancer Institute and the Food and Drug Administration, and the data from PDS has generated more than 15 peer accepted manuscripts in journals, and there are many more publications in progress</li> </ul>
<p><b>Collaborating Organizations/Partners</b></p>	<p>Project Data Sphere, LLC is partnering with Food and Drug Administration and the National Cancer Institute</p>

## Quantitative Imaging Biomarkers Alliance

### 5-year Cancer Moonshot Vision & Goals

- Establish standards (QIBA Profiles) for quantitative CT, nuclear medicine, MRI and ultrasound image acquisition, and analysis protocols for use in clinical trials so that imaging endpoint data are reproducible—improved reproducibility will facilitate precision oncology
- Work with the NCI Cooperative Group Network and the pharmaceutical industry to implement the QIBA Profiles in clinical trials
- Collect data to validate the claims in QIBA profiles
- Improve the value and practicality of quantitative imaging biomarkers by reducing variability across patients, sites, devices, and time

### First Year Progress on Cancer Moonshot Commitment

- Established 13 Biomarker Committees and 16 Task Forces that encompass 4 modalities: CT, MRI, Nuclear Medicine, and Ultrasound
- Established a comprehensive, systems-engineering, technical standards for image acquisition and analysis with QIBA profiles
- Collaborated with over 1,060 individuals to establish and improve the QIBA profiles

### Collaborating Organizations/Partners

QIBA is partnering with academic and private practice radiologists, imaging scientists, pharmaceutical companies, Imaging device companies, Imaging informatics and other software companies, government agencies, professional societies, clinical trialists and clinicians, statisticians and metrologists. Of those 1,060 participants, more than 300 individuals come from over 100 companies, 18 from the FDA, and 44 from other government agencies (excluding FDA). There are also QIBA affiliates in Europe and Japan

## SHARE For Cures

### 5-year Cancer Moonshot Vision & Goals

- Launch a data-sharing platform that makes it easy for anyone to access their personal health and wellness data through an easy-to-use interface, and then share their data with researchers looking for cures
- Run a pilot study of the real-world impact of cancer immunotherapy, collecting medical, wellness, and lifestyle data from patients taking this new class of drugs
- Develop patient-centered methods of data collection and aggregation of patient data from multiple sources over time

<p><b>First Year Progress on Cancer Moonshot Commitment</b></p>	<ul style="list-style-type: none"> <li>• Successfully launched SHARE platform and able to demonstrate that 99% of users would aggregate their medical, wellness, and lifestyle data in one place and share it with researchers</li> <li>• Recruited cancer patients on checkpoint inhibitors and collected clinical data confirmed the use of immunotherapy drugs—nearly all patients who enrolled set preferences to share all collected data for research</li> <li>• Raised funding needed to recruit individuals directly, speed research, and bring education and awareness to the power of data sharing</li> </ul>
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<p><b>Collaborating Organizations/Partners</b></p>	<p>SHARE For Cures is partnering with Lung Cancer Alliance and Melanoma Research Foundation</p>
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**Smart Patients**

<p><b>5-year Cancer Moonshot Vision &amp; Goals</b></p>	<ul style="list-style-type: none"> <li>• Make it even easier for patients to search for trials related to specific targets or targeted therapies</li> <li>• Encourage patients to initiate conversations in our online communities about cancer trials</li> </ul>
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<p><b>First Year Progress on Cancer Moonshot Commitment</b></p>	<ul style="list-style-type: none"> <li>• Made possible the ability to filter cancer trials by targets of interest in order to create more specific and relevant trial search results</li> <li>• Helped to expand conversation about specific clinical trials by opening patient-to-patient discussions within the Smart Patients community that allows patients to discuss trials and increase awareness</li> <li>• Integrated patient communities with patient registries in order to add a social layer which increases patient engagement</li> <li>• Worked with the Cancer Support Community to include the Cancer Experience registry as the first registry</li> </ul>
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<p><b>Collaborating Organizations/Partners</b></p>	<p>Smart Patients is partnering with the Colon Cancer Alliance and the Cancer Support Community</p>
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## Syapse

### 5-year Cancer Moonshot Vision & Goals

- Enable health systems to scale and systematize precision oncology programs
- Democratize access to precision oncology for patients in the community
- Catalyze data sharing efforts among health systems to surface promising treatment insights at the point of care

### First Year Progress on Cancer Moonshot Commitment

- Launched Syapse Data Sharing Network in June 2017 that enabled leading community health systems and academic medical centers to share clinical, molecular, treatment, and outcome data to improve patient care
- Allowed providers to view the treatments that offer the best outcomes for clinically and molecularly similar patients at different points of care thereby making it easy to incorporate into daily routine

### Collaborating Organizations/Partners

Syapse is partnering with Providence Health & Services, Stanford Cancer Institute, Intermountain Healthcare, Henry Ford Health System, and Aurora Healthcare

# Acknowledgements

The Cancer Moonshot: One Year Later was held by the Cancer Support Community (CSC), American Cancer Society Cancer Action Network (ACS CAN), CancerCare, Friends of Cancer Research, LIVESTRONG Foundation, National Coalition for Cancer Survivorship (NCCS), and the National Patient Advocate Foundation (NPAF).

Convening partners recognize the generous support of:

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# CANCER SUPPORT COMMUNITY.

*A Global Network of Education and Hope*

[www.CancerSupportCommunity.org](http://www.CancerSupportCommunity.org)

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