January 19, 2016

President Barack Obama and
Vice President Joe Biden
1600 Pennsylvania Avenue, NW
Washington, DC 20500

Dear President Obama and Vice President Biden,

On behalf of the millions of families who have been impacted by pancreatic cancer and lost loved ones too soon, I am writing you today to thank you for your leadership in announcing a new national initiative to cure the over 200 diseases we call cancer.

Pancreatic cancer has long represented one of the most significant challenges in cancer research with a five-year relative survival rate of just 8 percent. In a report released by the American Cancer Society this month, pancreatic cancer has surpassed breast cancer to become the 3rd leading cause of cancer-related death in the U.S. We released a report in 2014 that predicts that pancreatic cancer will become the 2nd leading cause of cancer-related death around 2020 unless we take critical steps now. The good news is that there has been tremendous progress over the last ten years in the development of the pancreatic cancer research community and we strongly believe that breakthroughs are possible if we can better facilitate an integrated research approach that puts patients at the center of the strategy.

In 2011, our organization announced a goal to double survival for pancreatic cancer by 2020. We also recently committed to raising $200 million by 2020 to launch groundbreaking patient and research initiatives. We plan to do our part to change outcomes for pancreatic cancer, but as you have so rightfully pointed out in your announcement of the cancer moonshot, one of the issues with expediting progress is an integrated approach across the cancer community. We need the help of the larger research community to cooperate, share data, and put the patient at the center of the system.

For example, this need to expedite progress, and also to ensure that each patient finds their best treatment, is the reason we created Know Your Tumor™ – our personalized medicine service designed to help the patient and their oncologist identify treatment options that offer the most hope for that individual. We believe that this service will not only help patients today, but also help patients...
in the future by prioritizing clinical trials that best match what real patients need. We have also recently launched an online Patient Registry, giving pancreatic cancer patients the opportunity to record and easily access the details of their disease experience. Patients have the option to share their information with the research community, and if permission is granted, we will provide this information to researchers to help answer important questions and disseminate best practices.

Today we are working to launch another cutting-edge clinical initiative – Precision Promise. The overarching objective of Precision Promise is to change the treatment paradigm for pancreatic cancer and establish a biomarker-driven stratified therapeutic approach. Precision Promise will use an adaptive clinical trial design that will incorporate information and learnings from both research activity and clinical experience and will be designed specifically for each patient, rather than the standard approach of finding patients that fit the characteristics dictated by the trials. The ultimate goal is to provide molecularly driven, evidence-based treatments for everyone facing pancreatic cancer.

Both Know Your Tumor and Precision Promise have required our organization and our scientific advisors to think outside of the box – against the grain of how the current system treats pancreatic cancer patients in order to gather data, share information across the community, integrate the best science with clinical trials and ensure that the patient is at the center of all decision making. We believe a forward-thinking approach is the only way to break down barriers and change the traditional mindset so that when someone is diagnosed with a deadly disease like pancreatic cancer, the initial reaction is what we can do, rather than what we cannot.

While our organization is focused on pancreatic cancer, we have also taken a leadership role in bringing together the community of cancers for which we have made the least amount of progress. In 2008, we formed the Deadliest Cancers Coalition, which now includes over 20 member organizations, and worked with them to pass the *Recalcitrant Cancer Research Act*. As you well know, the statute was signed into law by President Obama in 2013 and defines recalcitrant cancers as those with a five-year relative survival rate below 50 percent. Recalcitrant cancers, which include eight site-specific cancers (brain, esophageal, liver, lung, myeloma, ovarian, pancreatic, and stomach), will make up approximately half of all cancer deaths this year. They are the cancers where we have made the least amount of progress and have the greatest opportunity. **We therefore strongly encourage you to include a focus on recalcitrant cancers as you move forward with your new initiative.**

**We would like to schedule a time for our organization’s leadership and members of our Scientific and Medical Advisory Board to meet with you to discuss how we can work with you on your moonshot approach.** We believe we have a good perspective of a disease where answers seem insurmountable and only through new and shared approaches can we break down barriers and change outcomes.
Thank you again for your leadership on this critical new initiative. We look forward to learning more about how we can partner with you to cure all forms of cancers, including the recalcitrant cancers, like pancreatic. Please contact Megan Gordon Don, Vice President of Government Affairs & Advocacy, at 202-742-6776 or mgdon@pancan.org, to schedule a meeting.

Sincerely,

Julie Fleshman, JD, MBA
President & CEO