Mr. Chairman and members of the Subcommittee:

My name is Megan Gordon Don; I am here on behalf of the Pancreatic Cancer Action Network as well as the Deadly Cancer Coalition, a coalition of organizations that represent high mortality cancers, defined as those with five-year survival rates below 50 percent. I appreciate the opportunity to testify today regarding deadly cancers and the state of cancer research.

I'm going to give you some background on the research problems associated with deadly cancers and why the Deadly Cancer Coalition was formed as well as provide you with four key recommendations for the Committee's consideration.

I would like to first provide some background on what are best described as the deadliest cancers. While a number of cancers have achieved five-year survival rates of over 80 percent since passage of the National Cancer Act in 1971, and the average five-year survival rate for all cancers has increased during that time from 50 percent to 66 percent, significant challenges still remain for other types of cancers, particularly the most deadly forms of cancer. In fact, nearly half of the 562,340 cancer deaths in 2009 were caused by eight forms of cancer with five-year relative survival rates of less than 50 percent: ovary (45.5%), brain (35.0%), myeloma (34.9%), stomach (24.7%), esophagus (15.8%), lung (15.2%), liver (11.7%), and pancreas (5.1%). I have provided for the record a fact sheet on the deadliest cancers.

It is no coincidence that cancers with significantly better five year survival rates, such as breast, prostate, colon, testicular, and chronic myelogenous leukemia, also have effective treatment options – in some cases, several – and/or early detection tools thanks to research programs championed and supported by Congress. By contrast, research into the cancers with the lowest five-year survival rates has been relatively under-funded, and as a result, these cancers have no early detection or treatment tools. Available treatment protocols for many of the deadly cancers are still considered controversial. In further contrast, while there has been some work through The Cancer Genome Atlas (TCGA) for lung, brain, and ovarian cancer, which are three deadly cancers, biomarkers have yet to be identified or validated for the majority of deadly cancers. Also, survival for these cancers is measured in weeks and months, rather than years.

As grim as the statistics are now for the deadly cancers, the future looks even bleaker. According to an article in the June 2009 edition of the Journal of Clinical Oncology, cancer incidence is not only projected to dramatically increase in the next 20 years, but "certain cancer sites with particularly high mortality rates, such as liver, stomach, pancreas, and lung, will be among those with the greatest relative increase in incidence." In fact, the article projected that lung cancer incidence would increase by 52 percent, pancreatic cancer would increase by 55 percent, liver cancer would increase by 59 percent and stomach cancer would increase by 67 percent.

Our coalition started with the premise that all cancer patients deserve *at least* a 50-50 chance of survival. And, *at a minimum*, survival from all types of cancers should be above the starting line that was established 30 years ago when the overall cancer survival rate was 50 percent. The fact remains that there are a number of cancers, which make up nearly half of all cancer deaths

annually, that have not yet reached that starting line and in most cases are not even close. This shortcoming indicates that the time has come to establish a targeted effort to focus on the greatest challenges with the greatest need: the high mortality cancers.

Research into high mortality cancers has faced many hurdles including: low priority status, little accountability, below average funding, little understanding of the research complexities by grant reviewers (high mortality research grants are rarely reviewed by experts in that field), and a shortage of available tissue for research caused by the complexities of the diseases. To help you better understand what these hurdles have actually meant in the fight to increase survival for patients diagnosed with one of the deadliest cancers, I would like to use pancreatic cancer as an example. With a five year survival rate of just 5 percent, it is the deadliest of the deadly cancers.

It is estimated that over 42,000 Americans were diagnosed with pancreatic cancer in 2009 -- a 12 percent increase over the year before. In the past few years there has been increased publicity of this deadly disease with the deaths of Patrick Swayze, the actor, Dr. Randy Pausch, a computer science professor at Carnegie Mellon University and author of the widely acclaimed "Last Lecture", as well as the diagnosis of U.S. Supreme Court Justice Ruth Bader Ginsberg.

But while these prominent individuals' diagnoses have increased national awareness, the fact remains that a pancreatic cancer patient diagnosed today has roughly the same chance of survival as someone diagnosed 30 years ago. Today, 95 percent of pancreatic cancer patients die within five years of diagnosis. Seventy-six (76) percent die within the first year after diagnosis. There are still no early detection tools or effective treatments. Just as it has been for decades, the majority of patients diagnosed with pancreatic cancer hear that they should get their final affairs in order, instead of hearing about treatment options to help them see another birthday, wedding anniversary, or child's graduation.

Admittedly, pancreatic cancer is a particularly challenging disease to research:

- Pancreas tissue is very difficult to obtain for research. The pancreas is located deep within the body. Therefore, most tissue samples are obtained only if a patient has surgery to remove the tumor. However, because the majority of pancreatic cancers are caught very late, only 15 percent of all pancreatic cancer patients are eligible for this surgery. Further, even if tissue is obtained at the time of surgery, the tissue sample is usually small, making this resource extremely valuable and scarce.
- Pancreatic tumors are unique in the types of cells that make up the tumor. Tumors are often comprised of a variety of cell types, including dense fibrotic cells that may contribute to the remarkable resistance of the tumor to chemotherapies.
- Participation in clinical trials is often limited because patients are extremely sick and die quickly of the disease.
- Currently, there are no biomarkers sensitive and specific enough to be useful in the diagnosis of pancreatic cancer.

It should be noted that at this point studies have demonstrated that individual pancreatic cancer patients respond differently to various treatments. Therefore, personalized medicine holds great promise for people facing pancreatic cancer. However, as is the case for many of the deadly

cancers, much more research is needed to understand these differences, as well as a system to share data and analyze similarities and differences amongst individual patients.

These challenges in pancreatic cancer are not insurmountable. But, as with research into all of the deadly cancers, it will take leadership, vision and a change in the current research paradigm at NCI. Specifically, we are calling for an increase in funding, the creation of a targeted cancers program focused on deadly cancers to provide structure and accountability on making progress on these diseases, a dedicated grant program, and expert review of grants.

I want to note that our recommendations are not about telling NCI how to do the science. We simply believe that the status quo has not worked for deadly cancers and the time has come to take specific steps to ensure that there is sufficient focus on the deadliest cancers to ensure true progress.

Deadly cancers, like pancreatic cancer, are currently not research priorities at NCI and as a consequence they are severely underfunded. For example, pancreatic cancer currently receives less than 2 percent of NCI's nearly $5 billion budget – a figure much too low to foster any significant progress against this leading cancer killer. I have included for the record a chart of NCI funding for the top five cancer killers – which includes both lung and pancreatic cancer, also two of the most deadly cancers – and their respective survival rates. This chart demonstrates in very dramatic fashion that there is a clear correlation between low investment in research and poor survival rates. When an investment has been made, the five year survival rates reflect those efforts.

Funding is obviously an important part of the problem. NCI's budget has declined by nearly $700 million, or 15 percent since fiscal year 2003, after adjusting for inflation. More importantly, NCI has not made the deadliest cancers a funding priority. As indicated in the fact sheet on deadly cancers I have included for the record, less than 18 percent of the NCI's 2008 research funding budget was dedicated to the eight deadly cancers even though these cancers cause half of all cancer deaths. Across all types of cancer combined, the NCI spent just over $7,000 per cancer death in 2008. For the eight highest-mortality cancers, NCI devoted only about $2,500.

I do want to note that Dr. Barker has reached out to the Deadly Cancer Coalition about expanding TCGA to more of the deadly cancers. We are very interested in having TCGA address more of these cancers and, specifically, the most complex problems such as improving tissue collection methods when tissue is particularly scarce. However, while efforts like TCGA and nanotechnology are important parts of the solution for deadly cancers, these efforts on their own are insufficient. Targeted funding for research into deadly cancers also will be critical, but again, on its own, is not enough. Mr. Chairman, we believe that creating structure and accountability also is absolutely essential to making progress in these diseases. Specifically, the deadly cancer community recommends establishing a targeted cancers program within the NCI for the high mortality cancers. It should include a strategic plan for progress, an annual report from NCI to Congress, and a new grant program specifically focused on the deadly cancers.

The targeted cancers program would require the NCI Director to work with staff, top scientists, patient advocates and other stakeholders to develop a plan of research activities necessary to increase survival rates for the high mortality cancers. The strategic plan would identify the steps required to reduce mortality rates for each cancer over a five year period. The plan would include specific areas of research needed, as well as an estimated budget that can be factored into the NCI's Professional Judgment Budget. It would also include NCI-wide initiatives, such as nanotechnology and TCGA, to help ensure that all deadly cancers are included in these types of programs. The strategic plan will also have the added benefit of helping the deadly cancer research community ensure that privately funded research is not duplicating federally funded research. Furthermore, we believe that annual reports on the new program are necessary to ensure accountability. Reports should indicate progress that has been made against the plan in the previous year, changes in survival rates, and newly available early detection tools or treatments.

We also recommend the establishment of a new targeted grants program to create a protected pool of research funds for the deadliest cancers. Researchers studying deadly cancers often have relatively limited initial data, due in part to the historical lack of research into these cancers. In the NCI competitive application process, grant applications with limited initial data tend to be less competitive versus applications regarding more researched cancers, such as breast and prostate. Limited data reflects high-risk/high-reward research and the NCI tends to fund "safe bets." While researchers studying the deadly cancers would be encouraged to continue to submit proposals through standard grant mechanisms, they would also have the opportunity to submit grant applications under the targeted cancers program. This additional opportunity would help to compensate for the limited existing data in deadly cancers. For example, basic research investigating the biology and progression of some of these historically under-studied cancers may be considered high risk/high reward due to lack of research data available and would not receive funding. However, it is clear that the basic biology and progression of the disease are essential building blocks of knowledge, critical to moving these fields forward. With a targeted cancer program, these grants could be evaluated in a different way and would have greater opportunities to get funded.

Additionally, grants under this program could include a directed portion, similar to the challenge grant process the NIH used to administer ARRA funding, in order to meet the goals of the strategic plan discussed above. Funding would be open both to experienced investigators and to early-career investigators to attract more scientists to this field of study. Grant review committees would include scientific experts in the specific disease areas of interest, another critical point for deadly cancers.

We have presented the idea for a targeted cancers program to the NCI and have also been working with the House and Senate sponsors of the 21st Century Cancer Access to Life-Saving Early detection, Research and Treatment (ALERT) Act. Chairman Pallone, on behalf of the deadly cancer community, I would like to commend you and Representative Capps for your leadership in drafting a House version of this bill that would establish a targeted cancer research program and many of the ideas outlined above.

Additionally, for the pancreatic cancer community, passage of HR 745, the Pancreatic Cancer Research and Education Act, introduced by Representatives Anna Eshoo and Ginny Brown-Waite, is another important step to tackling the challenges I have discussed. Specifically, this bill would put in place a strategic plan for pancreatic cancer research and establish a cancer research incubator pilot project for the highest mortality cancers. The bill would also strengthen and expand Centers of Excellence for pancreatic cancer and promote awareness of the disease amongst health professionals and the public.

The time has come to tackle the hardest and most complex problems. We must fund new progress and give researchers the opportunity to do more with more, not less. It is by solving the hardest problems that we will likely see the greatest rewards for the entire field of cancer research. We have seen greatly reduced mortality rates of diseases like breast cancer, prostate cancer, AIDS and childhood leukemia as a result of targeted, comprehensive and well-funded programs. These research programs have produced early detection tools and effective treatments for these cancers. We must also shine a bright light on the deadliest cancers to achieve these same results.

Mr. Chairman, in conclusion, I want to thank you and members of the subcommittee again for allowing me the time to testify. Creating a targeted research program for the deadly cancers that includes a strategic plan and a dedicated grants program reviewed by scientific experts in the respective fields, is a critical first step toward reducing the mortality rates and developing early detection tools and treatments for the deadliest cancers.

The Pancreatic Cancer Action Network, along with the Deadly Cancer Coalition, hopes that in the near future a diagnosis of ovarian, brain, myeloma, stomach, esophageal, lung, liver, or pancreas cancer does not carry an automatic death sentence, but rather the first step in effectively treating and ultimately curing the disease. With your help, we know this hope can be a reality for all cancer patients.

In addition to the Pancreatic Cancer Action Network, this testimony is endorsed by the following organizations:

American Association for the Study of Liver Diseases
American College of Gastroenterology
American Gastroenterological Association
American Liver Foundation
American Pancreatic Association
Digestive Disease National Coalition
Esophageal Cancer Action Network (ECAN)
Hepatitis B Foundation
Hepatitis Foundation International
International Myeloma Foundation
Leukemia & Lymphoma Society
Lung Cancer Alliance
National Brain Tumor Society
National Ovarian Cancer Coalition
National Pancreas Foundation

Ovarian Cancer National Alliance
Sarcoma Foundation of America
Society of Gynecologic Oncologists

Attachments:
The Deadly Cancer Fact Sheet
Top 5 Cancer Killers Chart