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PANCREATIC CANCER: FIGHTING THE WORLD'S TOUGHEST CANCER IN ALABAMA AND NATIONALLY

HEARING

BEFORE THE

SPECIAL COMMITTEE ON AGING

UNITED STATES SENATE

ONE HUNDRED SIXTEENTH CONGRESS

FIRST SESSION

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PANCREATIC CANCER: FIGHTING THE WORLD'S TOUGHEST CANCER IN ALABAMA AND NATIONALLY

FRIDAY, NOVEMBER 15, 2019

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Washington, DC.

The Committee met, pursuant to notice, at 9:33 a.m. (CT), at University of Alabama at Birmingham, West Pavilion, Conference Room E, 615 18th Street South, Birmingham, Alabama, Hon. Doug Jones presiding.

Present: Senator Jones.

OPENING STATEMENT OF SENATOR DOUG JONES

Senator JONES. This hearing will come to order. Good morning, and welcome to a field hearing, an official U.S. Senate field hearing, Pancreatic Cancer: Fighting the World's Toughest Cancer in Alabama and Nationally.

I am pleased to once again have the opportunity to bring the work of the U.S. Senate here to Alabama, the Special Committee on Aging, of which I am a member.

I would like to extend my thanks to the Chairwoman of the Committee, Susan Collins of Maine, and the Ranking Democrat, Bob Casey from Pennsylvania, and all of their staffs for help in getting this hearing and facilitating this hearing today. Also, it is appropriate because we are here during Pancreatic Cancer Awareness Month. I see a lot of purple around here, a lot of purple ties, purple shirts, purple T-shirts, and purple ribbons.

I also want to thank our witnesses that we have with us today. Whether by profession or circumstance, each of our witnesses have become somewhat of experts on pancreatic cancer. I am grateful for your willingness to share your stories, unique perspectives with the Aging Committee, and hope that our conversation today will help bring awareness as well as bring us closer to a cure.

As too many of us in this room know firsthand, pancreatic cancer takes a devastating toll on families and communities across the State and the Country. So many lives are touched by cancer in general, but in particular, pancreatic cancer is a deadly disease.

Last year, although my family has had run-ins with different forms of cancer over the years, last year I became one of the millions who lost a loved one to pancreatic cancer when my dear friend Giles Perkins lost his life to this terrible disease. I am grate-

ful to have Giles' wife and also a dear friend, Hillery Head, with us today to honor his memory.

As Hillery will describe in detail, Giles fought pancreatic cancer for almost 3 years. During this time, he continued to serve as one of the State's most successful attorneys. He served as a community leader, a devoted father and husband, and all the while during the months of the latter part of 2017, running my campaign as the campaign manager and director. Throughout his life and even after his death, Giles has continued to make Alabama a better place.

It is fitting that today's hearing is held only blocks away from Railroad Park, one of his greatest contributions to this City and State. His tough-love approach and ability to see a bigger picture made me a better person, a better candidate, and now a better United States Senator. He was such a force in my life and throughout my campaign that I harken back to my days of Star Wars fanship and began calling him "Yoda." I will be forever grateful for his friendship, and today in my office in Washington, DC, we have one of our conference rooms named after Giles Perkins with a Yoda doll sitting in the corner.

Unfortunately, Giles is one of many Americans and Alabamians who have lost their lives to pancreatic cancer. This year, more than 56,000 Americans will be diagnosed with pancreatic cancer. The disease has one of the lowest survival rates of any form of cancer, with less than 9 percent of patients surviving 5 years after the initial diagnosis. In 2019, this disease is expected to claim nearly 46,000 lives across the County and over 700, approximately 770, in Alabama.

Like all cancers, the earlier you catch pancreatic cancer, the better your odds of survival. Unfortunately, pancreatic is extremely difficult to identify in its early stages.

As our witnesses will describe, most patients present few early stage symptoms, and there are currently no early detection test for this disease.

Research is critical to improving our understanding of this disease, creating new screening and diagnostic tools, and developing better treatments for patients.

That is why I have continued to advocate not only for increased funding for the National Institutes of Health and National Cancer Institute, but also for dedicated pancreatic cancer research funding within the Department of Defense.

Most folks do not know that the Department of Defense performs medical research. However, the DoD's congressionally directed medical research program is one of the most innovative and impactful research programs in the Federal Government.

Here at UAB, it is funded groundbreaking research into breast cancer and other diseases. Given pancreatic cancer's significant impact and dismal survival rate, it is critical that some of these dollars are directed toward pancreatic cancer research.

We have got a lot to do in order to develop better treatments, diagnostics, and ultimately a cure for pancreatic cancer. However, with the exciting research occurring here at UAB and across the Country and our States' inspiring community of family and patient advocates, there are also a lot of reasons to be hopeful.

With this hearing, I hope to honor our loved ones and explore the current opportunities and challenges in pancreatic cancer treatment and research. I look forward to hearing each of the perspective and insights from our witnesses.

I want to turn this over now to our witnesses. I will introduce them and then let them talk for a little bit.

By the way, we will be able after the conclusion of this hearing to have any comments or questions from the audience. What I will end up doing is gaveling the official hearing to a close, and then we can open that up to questions or comments from members of the audience.

First, we are going to hear from my dear friend, Hillery Head. As I mentioned, Hillery's husband, Giles, was a prominent community activist in Birmingham. He was diagnosed with stage IV pancreatic cancer in the spring of 2016, just weeks after experiencing his first symptoms, and he passed away last December.

As CEO of Ram Tool Construction Company and the mother of three, Hillery continues Giles' legacy of leadership and service.

Next, we will hear from Ms. Lynette Nall. Ms. Nall is a retired telecommunications staff manager from Pleasant Grove. She lost her daughter, Letisha Nall Palm, to pancreatic cancer this past January. After months of discomfort, Tish was diagnosed with stage IV cancer in June 2017 at the age of 45.

Ms. Nall will share with us her daughter's story and discuss the importance of improving treatments and diagnostic tools.

I am also grateful to have Mr. Steve Cook here with us from Huntsville. Mr. Cook became involved with the Pancreatic Cancer Action Network, also known as PanCAN, just weeks after his wife, Marqueta, was diagnosed with stage IV pancreatic cancer. Since his wife's passing in 2018, he has become a fierce advocate for increased Federal funding for pancreatic cancer research, which he will discuss today.

I also have known Steve in his other capacity working for Dynetics in Huntsville and part of our military defense operations that we have, so we see each other on a regular basis.

Last but not least, we are going to hear from Dr. Bart Rose, the director of UAB's Pancreatobiliary. I do not know how in the world to pronounce that, to be honest with you.

Dr. ROSE. You are pretty close.

Senator JONES. Okay. All right.

The disease center was established in 2018. The center links medical professionals from UAB and Alabama to ensure that patients with pancreatic cancer and other conditions affecting the pancreas, gallbladder, and bile ducts receive appropriate and modern care.

Today Dr. Rose will discuss the current State of pancreatic cancer treatment and research.

Thank you all so much for being here, and I will turn it over to each of you now.

Hillery?

STATEMENT OF HILLERY HEAD, LOST LOVED ONE TO PANCREATIC CANCER, BIRMINGHAM, ALABAMA

Ms. HEAD. Thank you, Senator Jones, members, and staff. Thank you for the opportunity to share my family's story.

As Doug just said, my name is Hillery Head, and I am a mother, a businesswoman, and a native Alabamian. I am also a widow from pancreatic cancer.

In the spring of 2016, my husband, Giles Perkins, began feeling under the weather. His health declined rapidly, and none of the antibiotics he took seemed to help. I urged him to see my primary care physician, who ran him through a battery of tests and diagnosed him with stage IV pancreatic cancer. It was the day before our eldest child graduated from high school.

Of course, we were stunned. The only reason I believed the diagnosis was that it offered an explanation of how Giles had gone from an active and vibrant 48-year-old to a jaundiced invalid in a matter of weeks.

Always realists, Giles and I faced the fact that our family had to learn how to live with cancer quickly. In the same manner we had approached problems throughout our 25-year marriage, we weighed what was in our favor and what was not.

There is no doubt we had a terrible diagnosis, but we had also a number of things in our favor. We had three healthy, grounded children. Two of our children were old enough to drive and help out. We had supportive friends and family close by.

UAB's O'Neal Comprehensive Cancer Center, world renowned, was only 2 miles from our home. Dr. Selwyn Vickers, a renowned pancreatic cancer specialist, was at UAB and helping us.

We both worked jobs that allowed flex time. We had very little personal debt. We had first-class health insurance, and we knew it would remain in place throughout the course of the disease.

In many ways, we faced this terrible diagnosis with the world in our favor, and we were acutely aware of how lucky this was, and so we started down the path of living with cancer. Chemo started, and Giles responded well. With our children, we made a conscious decision to live each day as a gift and not to mourn Giles until he was truly gone from us.

Fighting the disease was very difficult. Chemotherapy is poison, and the effects of the poison, while it drove back the cancer—and I was so thankful for that—it took away Giles' ability to hear. It caused debilitating pain in his hands and legs and made mobility an issue for a previously active 48-year-old.

The stress and trauma of watching Giles battle this illness took a toll on him, on me, and on our three children. Again, we had the luxury of support through counselors, spiritual leaders, good friends, and family. We had the luxury of connection to our children's schools, to Giles' doctors, and to the community. People knew what was going on, and people cared, and so the fight continued for 3 years. When known chemo stopped working, we moved on to more experimental combinations, and when those did not work, we moved into the stage of managing pain. "Managing pain" is a benign term for a terrible situation. The pain is so debilitating that Giles could not think or function without massive amounts of

pain medication. For those of you who do not know, to watch someone you love in pain, it is suffocating.

Again, we took stock of what was in our favor. The UAB palliative care group was 2 miles from our house. The palliative care group was available to talk 24/7. We hired wonderful caregivers to help Giles while I continued to work. Giles could tolerate high doses of pain medication, and he continued to work from home, sometimes more actively than we wanted him to.

His brain continued to be sharp, his spirits remained high, and he continued to want to live and to want to contribute. As Doug said, he wanted to make Alabama a better place.

Despite all that was in our favor, on December 2d of last year, Giles passed away. He died in our home, surrounded by friend, family, and people who loved him. He fought this disease from beginning to end with every fiber of his being. He knew, and I knew, how very lucky we were that in the midst of this great misfortune, he could still do what he felt was his life's work, and so I leave you with these thoughts. Cancer does not care how young you are, how educated you are, how good your job is, how much money you have, what religion you have, how many marathons you have run, how much your children need you, how much you have left to do on this earth. Cancer does not care, and so it is up to us to care. It is up to us to support, to fight, to fund, to help, to love, and to live every day like it is a gift from God. It is up to us to support families facing this same disease and, most importantly, find a cure.

Thank you for listening to my family's story.

Senator JONES. Thank you, Hillery. Thank you.

Ms. Nall?

STATEMENT OF LYNETTE F. NALL, LOST LOVED ONE TO PANCREATIC CANCER, PLEASANT GROVE, ALABAMA

Ms. NALL. Yes. I am Lynette Nall, and I am going to tell Letisha's story. We called her "Tish."

Tish was my firstborn child, born February 5th, 1972. She was a healthy child, growing up, only to see the doctor for annual physical exams each year. As she grew into adulthood, she was still healthy, eating healthy, exercising on a regular basis. She was a devout Christian, married with three children: Kirsten, 23; Dexter, 21; and Selice, 9.

In February, Tish, as we called her, started having trouble getting comfortable when laying down, and that was February 2017. She said no matter how she would lie down, she could not get comfortable and had trouble sleeping. Tish had light pain in her lower back. She went to see her primary care physician, but he could not find anything wrong. She went on with the light suffering for about 3 months.

In May 2017, my husband Ronald, Letisha, Kirsten, Selice, and myself took Kirsten to Iowa for a summer job and to attend the University of Iowa. Tish was still uncomfortable but tolerated the pain. We stayed in Iowa 3 days. Upon our return back, Tish's pain got a little worse. She got extremely nauseated, and we had to stop on the side of the road. The nausea was the worst I had ever seen. It just appeared that everything inside of her came out in that car. We proceeded on the road trip but stopped at the next exist at a

CVS and picked up three nausea medications—one for the hand, two for the mouth—to try to control it. We made the trip home without another nausea episode.

On June 23, 2017, Tish dropped Selice off at my home, as she did every Friday. She did not look well but said that something she smelled at the church made her sick. She said she would go home and rest, but the next call we received was from St. Vincent's emergency room. She drove herself to the hospital. She left the house and went straight to the emergency room.

I told my husband to go to the hospital and that I would come in the morning to relieve him. Ronald called later in the night to let me know she would be admitted to the hospital and would be on the oncology floor. That was something I did not expect to hear.

A biopsy was performed in June 26, 2017. The diagnosis on June 27th was pancreatic cancer stage IV. All of us were devastated. Dr. Ira Gore was the oncologist assigned to Tish's case. However, she was suffering from some mental abuse from her husband, causing her much stress. She moved in with my family until her death in January 2019.

On July 12th, 2017, Dr. Gore started her on Gemzar and Abraxane cocktail chemotherapy, 3 weeks on and one off, and that treatment regimen lasted until November. Tish had the month off for December, but her blood counts were low, and she needed a break from treatment. Her tumor marker went from over 80,000 to around 1,000. It was better but far from normal. Tish appeared to be improving, and she was sweet, strong-spirited, and very positive. Her faith was strong.

In January 2018, tumor markers went up again. Tish was also having severe back pain, nausea, and constipation. She was highly fatigued. Meds were used to resolve those issues. So Dr. Gore decided to try immunotherapy: Keytruda. The pain worsened with the Keytruda. Pain meds were increased. Keytruda stopped after two treatments. Tish started feeling pain under her rib cage that Dr. Gore contributed to the cancer that had spread to her liver.

In March 2018, Dr. Gore changed the treatment to 5-FU. This regimen continued until September 2018. By this time, her tumor markers had gone over 184,000. She was also extremely tired and weak. Her blood counts were low.

In October 2018, Dr. Gore changed the treatment regimen to Xelodal 2 weeks on, 1 week off. He also referred Tish to Dr. Shaib, the Emory Winship Cancer Institute in Atlanta. Dr. Shaib qualified her for a trial but wanted to wait and see if the Xelodal would work. He did state that the Keytruda would have probably worked had she stayed on it longer. He advised that the Keytruda causes the cancer to swell. It gets better; hence, that is why she had an increase in her pain. Visits to Atlanta were done monthly.

In December 2018, Tish was very short of breath. Dr. Shaib requested to take her to Emory ER. She had fluid on her lungs that had to be drawn off by the pulmonary. She had a thoracentesis. This fluid drainage had to be done twice more in January. She also started retaining fluid in her abdomen. That had to be drained as well, a paracentesis. Tish was also in intensive care for several days for blood clots on her lungs. She was released in the care of hospice.

On January 30th, 2019, after a few days at home, Tish succumbed to the disease in bed early that morning. Needless to say, there should be early detection for this disease. Tish's first visit to the doctor should have resulted in some test that could have saved her life, with all the trials that have been done and still going on for this cancer. The trial and error methods were frustrating for Tish and for our family that allowed her to suffer more than necessary.

In closing, Tish was a healthy person. She was a sweet person, and she held her faith until the end.

Pancreatic cancer and any other diagnosis that was detrimental to her health was unacceptable due to her healthy past. Early detection could have saved her life, given her early treatment options to extend her life. Any tools, diagnostic tools, should have been given her to increase her lifespan, affording her the opportunity for life-saving trials.

I cannot say it enough. Early diagnosis is the key to survival. Our survival depends on it.

Thank you.

Senator JONES. Mr. Cook?

STATEMENT OF STEVE COOK, PANCAN ADVOCATE, LOST LOVED ONE TO PANCREATIC CANCER, HUNTSVILLE, ALABAMA

Mr. COOK. Senator Jones, good morning, and welcome to everybody here this morning.

On behalf of the Pancreatic Cancer Action Network, or PanCAN, I want to thank you for convening this important hearing today to highlight this just terrible disease, and I can say that I feel very much the same way as Ms. Nall and Ms. Head in the things that they went through and the things that they experienced, and it is something we need to solve. We have got to solve and beat this problem back.

The importance of Federal support for pancreatic cancer research is incredibly important, and I will talk some more about that.

I am here today because my first wife, Marqueta, died from pancreatic cancer, and I am also honored to represent the pancreatic cancer community, including pancreatic cancer patients, families, and researchers from across the country.

PanCAN is a leading patient advocacy organization focused on pancreatic cancer, with a goal to dramatically improve patient outcomes.

When Marqueta was diagnosed with stage IV pancreatic cancer on Father's Day weekend of 2017, my family and I were dumfounded. It felt like we had been hit with a Mack Truck. It is not something you could ever imagine coming when you went in for one particular diagnosis, thinking it was something, and then learning actually accidentally in the hallway overhearing a nurse talk about it in the hall.

At that point, we just did not quite know what we were going to do, but we also quickly realized this was going to be the fight of her life, and we all had to rally around it. We had wonderful friends, our church. Most importantly, we had a relationship with God that strengthened us and got us through this.

As an engineer, I like to solve problems, and I knew that I needed to learn more about this terrible disease, so I reached out to several resources, including PanCAN. Our doctor told my then student son, engineering student son, and I to help engineer a solution, and so we dove in and looked up all the research that was going on, what was happening, and asked many, many, many questions. Probably her doctor got tired of hearing the questions.

As she continued to battle the disease and we began learning more about pancreatic cancer, I realized that funding for research was a core challenge. Recognizing that one of the strongest weapons that we have in fighting this disease is Federal research funding. Marqueta encouraged me to take the message to our leaders in Washington, DC.

I attended my first PanCAN Advocacy Day in 2018, about 2 weeks after she died, just 12 months after her initial diagnosis. Truth be told, I considered not going, but I knew she had wanted me to go. She told me she did, and I am really glad that I did. This disease can render you hopeless, but taking a unified message to the Hill with hundreds of others was inspiring. We all had a shared bond, as we all do here this morning.

My story is unfortunately far too common. Sixty-five percent of patients die in their first year of diagnosis. This year alone, the numbers are up. 57,000 will be diagnosed with pancreatic cancer, including an estimated 910 from this great State. Pancreatic cancer is currently the third leading cause of cancer-related death in the United States and expected to become the second leading cause of cancer death by 2030.

While survival rates for many other cancers have improved—and thank the Lord for that—the 5-year survival rate for pancreatic cancer is only 9 percent.

Thanks in large part to the step Congress took in addressing pancreatic cancer, the National Cancer Institute is making progress and providing new research opportunities for pancreatic cancer. While there has been a slow increase in the Federal investment in pancreatic cancer, the research funding remains disproportionate to its severity.

Along with the NCI, the Department of Defense is an important source of funding for cancer research. The Department of Defense focuses on high-risk, high-reward research, an important complement to the work that NCI does, and it is critically important for a disease like pancreatic cancer.

Veterans have also had several risk factors that show up for pancreatic cancer from things like environmental factors that they run into.

Thank you, Senator, to you and to your colleagues, over the last few years, Congress has provided funding annually for pancreatic cancer research through the Peer Reviewed Cancer Research Program at the Department of Defense. This funding has provided a small but important amount of support for this innovative and competitive cancer research. However, only a very few ever make it through this competitive process, and so only a few grants get through each year. In fact, in Fiscal Year 2018, out of the 80 cancer grant applications for pancreatic cancer, only five got recommended

for funding. We can do better than that, and we must do better than that.

A more focused pancreatic cancer research effort at the DoD is desperately needed. We all believe a positive step forward is the creation of a new and dedicated DoD research program for pancreatic cancer.

In June, the House took an important step when it approved its version of the Fiscal Year 2020 Defense Appropriations Act. Thanks to bipartisan leadership, the House bill now includes $6 million for a new dedicated pancreatic cancer research program.

As you know, the Senate version of the bill marked up by the Appropriations Committee in September does not today include any funding for this new pancreatic cancer research program.

As a result, due to the complicated budget situation that I know you are very well familiar with, it appears that our best approach moving forward is to increase the House-approved amount to $10 million in the final conferenced versions of the Defense Appropriations Act.

Sir, I hope that you will continue to champion that request and work with your colleagues on the House and Senate Appropriations Committees to make sure that the new Pancreatic Cancer Research Program is approved at $10 million. I am extremely appreciative of the work that you have done and your leadership on behalf of this request.

As has been noted, pancreatic cancer does not discriminate. Notable figures of recent notoriety like Alex Trebek, the game show host, and very recently Supreme Court Justice Ruth Bader Ginsburg have been diagnosed with this disease.

This is not a blue or a red issue. We tend to get all tied up, particularly in Washington, DC, with Democrats versus Republicans, and it is incredibly unfortunate. No, this is not blue or red. This is literally purple. This is a purple issue.

I found myself crying and praying in the office of a Senator with different political views than me. I noted earlier going through this disease bonds you with others, you become part of a community, a community that is committed to saving lives, and that is why I am here today. The time is now.

Senator Jones, on behalf of PanCAN and the thousands of American families who just like me have lost a loved one to pancreatic cancer, I want to thank you again for holding this hearing today. We look forward to continuing to work with you and your team to change the lives of those in Alabama, across our country, around the world with those and families who have been diagnosed with this deadly cancer.

Thank you.

Senator JONES. Thank you, Steve.

Dr. Rose?

STATEMENT OF J. BART ROSE, MD, MAS, DIRECTOR, PANCREATOBILIARY DISEASE CENTER, UNIVERSITY OF ALABAMA, BIRMINGHAM, ALABAMA

Dr. ROSE. Thank you very much, Senator Jones, for having me today and to the Special Committee on Aging for setting up this hearing and to the audience for being here today.

I again would like to thank you for the opportunity for testifying on the State of pancreatic adenocarcinoma, or pancreas cancer, care in the United States in 2019.

Pancreatic adenocarcinoma is a leading cause of cancer-related death in the United States. Depending on the source, it is the third or the fourth most common cancer-related death, causing death in the United States, but it is projected, as we heard before, to be the second by 2020 due to a rising incidence of nearly 2 to 3 percent per year over the last decade and this has been pretty consistent.

We have seen, unfortunately, a stagnant rate of 5-year survival of about 9 percent. This is due in large part to the fact that over half of patients, unfortunately, will present with metastatic disease or disease that spread to another organ when we find it, and treatment options there, as we have heard, are rather limited.

At this time, this advanced disease is very difficult to treat, and most patients will succumb to their cancer.

Within in the State of Alabama, we predicted 910 new cases of pancreas cancer will be diagnosed this year, and unfortunately, about 770 people will lose their lives to this disease.

Alabama has a higher death rate related to pancreas cancer than would be predicted. Our State has the ninth highest pancreatic cancer death rate in the United States, even though it only ranks as the 21st highest rate for new cases.

Among the health care workers who have had the privilege of helping patients with pancreas cancer, improving survival from pancreas cancer is our top priority.

The poor survival in Alabama compared to other States may be due to disparities in cancer outcomes seen between Caucasian Americans and African Americans. We know that African Americans with pancreas cancer have up to a 3 percent increased risk of death over a Caucasian patient. Since African Americans comprise nearly 27 percent of Alabamians, our State is more diverse than most other States, which means that this difference in pancreas cancer survival is compounded compared to other more northern States with less African American representation.

We know that of the 25 percent of patients who are eligible for an operation to remove their pancreas cancer, only 40 percent are ever offered this potentially lifesaving operation. This is a huge opportunity to help Alabamians with pancreas cancer, as surgery is generally the only option for cure in combination with chemotherapy and sometimes radiation. This disparity in access to lifesaving operations is even worse for African Americans.

To make any significant impact in the survival of this devastating disease, we need to address a number of deficiencies in its care.

Number one: as the majority of patients will present with pancreas cancer that cannot be removed, we need better treatments for advanced-stage disease and the ability to detect disease at an earlier stage. Both of these require investment in medical research. In 2019, the National Cancer Institute was budgeted by Congress $6.1 billion. While seemingly an improvement over prior years, when adjusted for inflation, this has been stagnant for over a decade. Only $221 million or approximately 4 percent of the NCI budget was awarded to study pancreas cancer, which again remember is

the fourth leading cause of cancer-related death, only 4 percent. Private society funding like PanCAN is wonderful but is limited research in this disease compared to other cancers of higher incidence. There are much more societies that offer research funding for some cancers like breast cancer or colorectal cancer. As a pancreatic cancer researcher, I can state without question that investment in this area is desperately needed. The only way that we are going to move the needle forward in improving overall survival beyond the currently unacceptable 9 percent is by having better therapy for advanced disease and earlier detection.

Number two: we need to improve our outreach efforts into the community and encourage patients to be seen by qualified surgeons and cancer doctors to discuss potentially lifesaving operations. As a medical community, we need to break the unfortunately nihilistic perception of pancreas cancer and spread our message of hope. Primary care providers need to be informed this can be a curable disease.

Number three: we need to address disparities within health care, including those within pancreatic cancer. In the Deep South where we celebrate our diversity with a large proportion of African Americans, this disparity is particularly relevant. Additional money should be made available to study and reverse these disparities.

At the University of Alabama in Birmingham, we are trying to address many of these above-stated issues. We have a number of basic and translational science projects dedicated to advancing the study of this disease as well as focusing on dipartites present in the Deep South. We are the largest treatment center in this region for pancreatic cancer and are focused on providing modern multidisciplinary care through our dedicated Pancreatobiliary Disease Center.

We would like again to thank the Committee for the opportunity to testify. Thank you.

Senator JONES. Thank you, Dr. Rose. Thank you all to our panelists. Thank you.

Dr. Rose, I want to come back to you first because we keep hearing that pancreatic cancer is going to be soon the second leading cause, and I am always truck how a cancer continues to go up the ladder a little bit. Is there research or is there any promising research about the causes of pancreatic cancer that we are seeing more and more of these days?

Dr. ROSE. Yes. I think there is a number of risk factors that we have identified for pancreas cancer. Most of them are causes of inflammation in the pancreas, and I think that we are seeing a rising incidence of some of those risk factors—diabetes, obesity. Unfortunately smoking, it seems to be rising again. I think that may be contributing to the rising incidence and then the other thing that is causing it to climb up that list being the most deadly cancers is actually good news in that we are getting better treating some of the other top cancers, so, as their survival improves, we jump up the list because we are not, and I think that is just where that funding needs to come in to advance the basic science to tackle new treatments and diagnostic therapies.

Senator JONES. All right. We will come back to that.

Mr. Cook, you mentioned after your wife's diagnosis, you reached out to PanCAN, and I am sure all of you may have reached out for other resources. What resources did you find that were especially helpful for you and your family, and are there other resources out there? PanCAN is obviously a wonderful one. Are there other resources?

This was really to all three of you. What are other resources out there just in helping dealing with this?

Mr. COOK. Senator, thank you.

One of the first calls I did place, once we were diagnosed with the cancer—notice I say "we" because this becomes a family fight. This is everybody in this when you get on top of this, and one of the things she did when she said, "I am not going to have the energy. I need you to go do the research," my son and I and my daughter all dove in and looked at that.

One of the things that I would encourage people not to do is just go off and do a random Google search because when you do that, you pull up some data that—I mean, it is wrong. It is already a difficult enough disease, but to pull up all the things that you pull up out there, I do not think it is helpful at all.

I will talk about PanCAN first and then talk about a couple others. PanCAN was one of the first calls. They have a call center out in California. I have actually been there, walked through there last year, and I will tell you they are trained professionals that know that most of the calls they get are from people in many areas in the rural community that their doctors are not very familiar with this. They know that you just got a death sentence handed to you, and sometimes that is actually what is told to the patients by their physicians. They are there to help understand, "Hey, this is what your options are. Here is the resources we can provide," incredibly caring people, and you have somebody on the other end of the phone, which is really nice to hear especially when you are going through something like that. Then they have a lot of resources on the website.

Another group that is very active and has some very good resources is the Lustgarten Foundation, and they are very active as well in battling pancreatic cancer. I would recommend them.

Then there is the medical research. If you want to dive in on the latest there—and the physicians can help you get access to this. You can get access for 30 days for free from your physician. It is a service called UpToDate, and it is something I am sure the doctor uses. You can get in and get as much information as you want and search it and read the latest research that is literally going on that is out there.

All of those kinds of things helped because both from an emotional perspective and from an information perspective, they were all very useful.

Senator JONES. Great.

Hillery, I want to ask you something because I want to come back to a more personal level now. You emphasized how important it was for Giles to stay active, and I know that that helped him. It helped the family. It was fortuitous, to some extent, I think, that he was able to get back into one of his—well, his second love, besides you and his family—into politics because of a U.S. Senate

race that was popping up. The last part through 2017, Giles was enmeshed in my campaign, and then immediately upon election, he helped put together the staff and stayed so engaged.

Can you describe that a little bit and how important it is for those that are diagnosed with this disease to find something to continue to, for lack of a better term, live for.

Ms. HEAD. Yes, yes. He did love the politics, Doug, and loved the State of Alabama. It was so important for him to remain active, and that was one of the hardest things about this disease because it robs you of your time, and it robs you of your energy, and it robs you emotionally. It is so draining.

We made a conscious—I made a conscious decision to help support him and let him focus on the things that he thought he could really change in his remaining time on this earth, and that had a lot to do with our children and spending time with our children.

Once you get beyond the family, to look and see sort of a greater goal for him—and his brain was always very active. Even when physically he was not able to get up and move around or do things like that, people would come to our home, you remember.

Senator JONES. Oh, yes.

Ms. HEAD. He would be on the phone all the time, and that gave him hope. The hope was really, really important because this disease can be so all-consuming.

Also, I keep feeling like I am plugging UAB, but you have to have UAB, and all the resources here are so close to our house and just a phone call away. That sort of support, I just cannot emphasize what a godsend that was for us.

Senator JONES. Well, it was important to a lot of people.

I will say on a little bit lighter note, I could always tell when Giles was undergoing chemotherapy because my phone would just be on fire with text messages and things I was not doing right. He was constantly telling me that I needed to do something better or different all the time, and I just have to put it down and leave it alone.

Senator JONES. He stayed that way right up until the end.

Ms. Nall, for about 3 months or so, you all had a difficult time. You just did not know. How difficult was it to try to figure out where your daughter should seek help and what was wrong with her? Any advice for people on that?

Ms. NALL. Well, at the time, the 3 months, we really did not—again, we never thought that it was anything close to pancreatic cancer. I would say today that if that were to happen again that I would seek a second opinion because I think even though she was healthy, she had a complaint. She had a problem, and that problem was not resolved and it should have been, and if not, to move on.

Tish was the kind of person that she was so caring, and she just trusted in her primary care physician. She trusted in her oncologist. I know what you are saying about UAB. She was at St. Vincent's. We tried to get her to change, but she wanted to stay with Dr. Gore. She trusted him.

It was hard, and it is the most dreadful disease that I had ever seen. It was hard to watch my daughter, who was so active, to all of a sudden kind of lose all that.

I would seek a second opinion, and I would also—I really learned a lot from the Cancer Center in Atlanta, Emory Winship, and Dr. Shaib was just—he was very kind, very open. She loved him. Actually, we did not go back to Dr. Gore until she went in the hospital. She had to see a local physician, and we did not want to change.

I got a lot of material there, and he discussed everything in detail in a way that we could understand. He brought the whole family in, all of her sisters and brothers, and that made it a good experience. It is just that she just kept going down. It was so much to deal with for her and for us as well.

Senator JONES. Well, thank you.

Dr. Rose, back to you. We have talked about funding for NIH, for the National Cancer Center, and we talk about cures for cancer. Everybody likes to say, "When are we going to get a cure for cancer?" I assume part of that is early diagnosis. That is what we keep hearing. One of the reasons why this disease—and there are some others too that are as deadly because of the inability to diagnose early enough.

Can you give us some hope? What is being done? What are we seeing there as possibilities on the horizon for the early diagnosis which can then lead to a cure or either the significantly longer extensions of life?

Dr. ROSE. Yes. I think there are certain types of cancer that early diagnosis is really the linchpin of being able to cure the patient, and the reason is that we just do not have good systemic or chemotherapy to treat it. We can keep it at bay, but it does not generally cure it.

The option for cure is being able to remove it, and you can only remove something if it is in a few spots. If it has spread throughout the body, it is just not possible, and that is where the kind of systemic therapy or chemotherapy comes into play, because we do not have good chemotherapy that can cure diseases spread throughout the body, we are relying on operations, and those are more likely to be possible for an early stage cancer.

In order to catch these cancers, we have to catch them in that period before they spread. There has been some really interesting studies that Johns Hopkins Group has really been pioneering this, looking at how long does it take a pancreas cancer to develop, and it turns out that it is not as fast as we think. It is probably closer like 20 years. When the cell first makes that genetic mutation that triggers the cancer, it is about another 17 years or so before we actually can recognize the tumor and then maybe another 5 years on average until the patient passes. It is somewhere between 20 and 23 years before that cancer starts and when it actually takes your life. There is this period in there that we can maybe catch this early.

I think looking at things, it would be tumor markers would be nice. People are looking at circulating tumor cells, cell-free DNA, or some of these things that you can sample patient's blood and look for evidence of a cancer before there is necessarily a mass.

The problem with that is that we are not quite at the level where we are certain that what we are measuring is what we are measuring, and that it is inexpensive enough that it could be done on a wide scale.

I think that plays into also that, thankfully, this is a relatively, compared to other cancers, rare cancer, and so that any kind of screening option we have to have, we have to recognize that we are only going to pick up 50,000 people a year. It has to be inexpensive enough that we could test all 3 million people in the United States to catch 50 million people. I think that is the other kind of realistic problem that we are dealing with.

Senator JONES. You mentioned disparities in funding for research. Is that because of the rarity of the cancer that there are not as many people? How is that funding decided?

Dr. ROSE. That is a great question, and I would have to defer to the NCI directors for that.

You know, I think that it has traditionally been because of the rarity of the disease, and so they wanted to kind of allocate money to where they had the most bang for the buck, so to speak.

As we are getting better treating some of these other cancers—and we are seeing this kind of rise in the severity in the rank of deadly cancers—I am hoping that they kind of reallocate money toward that where we can make some real big impact on some people. That amount of money, I think, is disproportionate to how severe the disease is, so I would like to see that increase.

Just, in general, funding at the NIH, I would like to see increased too because the payline or the percent of people that actually get their grant funded in the Cancer Institute is extremely low compared to the other institutes. I think it is the lowest institute in all of the NIH. It is somewhere around 6 percent get funded. That is six out of a hundred grants actually get funding, which is sad.

Senator JONES. Thank you.

Steve, you and Hillery, I believe Giles participated in a—did he participate in any clinical trials?

Ms. HEAD. They were not official clinical trials, but there was a lot of different variety of drugs and combination of drugs that he was trying in an effort to drive back the cancer.

After that initial—he had initial chemotherapy that really helped, and then that kept the cancer at bay for about a year. Then it started to come back, and so he did try the Keytruda. You know, there were others that he tried.

Senator JONES. Right.

Ms. HEAD. They were not official clinical trials.

Senator JONES. Okay. Steve?

Mr. COOK. Yes. Before I hop on that, I want to just jump on a point that the doctor just made——

Senator JONES. Sure.

Mr. COOK [continuing]. and to your previous question, the importance of that early screening. I will give you a real example of that, and that is, when she was diagnosed that Father's Day weekend, about 5 months prior, she had been in and had a kidney stone and had a full CAT scan done of her abdomen. As standard practice, they do not do a contrasted scan because they are looking for a stone, and it cost extra money to do that. If they had done a contrasted scan, they would have picked that cancer up at probably stage I versus at stage IV.

Senator JONES. Wow.

Mr. COOK. Just a few months earlier—and her doctors went back, pulled the scans, and looked, "Did we miss something?" They did not miss anything because there was no way to see that without that.

Let me say if you go in for an abdomen, some sort of an abdomen CT scan, pay the extra money, if your insurance will not do it. It is a couple hundred dollars, and it is well worth it to get that contrasted scan.

I will tell you, I have been by that room, and I will tell you it is just an eerie feeling when you go by there. You are like, "You know what? We could have caught it right then and there."

I will say also I think it is important for those that have had families that have had pancreatic cancer and even for others to have cancer screening, genetic cancer screening done. The HudsonAlpha Institute in Huntsville uses that, does that service. There are other providers through PanCAN, others you can get that done to see if this has been passed down. We want to know if this is passed to our children or not, speaking of genes.

Now to your question, we did a lot of research. We went up to Johns Hopkins, met with them, decided, all right, what was the right path. We ended up settling on doing a clinical trial run out of a cancer institute affiliated with Vandy in Tennessee. We got lined up to do that. You have to go through a certain set of things to get off the chemo to start that. As we did that, she had a secondary issue pop up, had to have surgery, had to get off the chemo. When you pulled that foot off the gas, which you had to do, then the cancer just got really, really aggressive. By the time she came out of that, she was no longer eligible for the trial, and she only lived for a couple months.

Senator JONES. Wow.

Dr. Rose, back to you for a moment. You talked a little bit about racial disparities that we have seen. I know UAB, in general, has been working on cancer, in general, and the racial disparities with cancer, which I really appreciate.

Has research thus far identified any factors that might contribute to a higher prevalence of pancreatic cancer in minorities?

Dr. ROSE. Yes, I think it is unclear. We do know that some of those preexisting—or those risk factors are a little bit more prevalent in some of the minority populations, diabetes and obesity, and so since those are a little bit higher, they may be contributing to it.

We have started to look at that within pancreatic cancer here at UAB, and when we look at patients who actually receive treatment and have an operation to remove their cancer, actually their outcomes are the same. There is no difference.

I think the big area to focus on is identifying it early and getting people referred to centers that are familiar with treating this rare disease, and as long as we can get people educated in the local communities kind of on the ground with their primary care doctors and again just focusing on referral and not on this concept of this being a death sentence, that this is either treatable and sometimes potentially curable, that you need to see somebody to talk about this in more depth.

Senator JONES. The access is always a problem. Access is a problem because there is also a disparity generally with rural and urban. We have got folks here that had UAB right at the door or St. Vincent's right at the door, but folks in rural areas have a harder time getting that and we are losing rural hospitals, and we are losing health care providers.

What can the State do or what can the Federal Government do to better give folks in those rural communities access to the care, access to the clinical trials? Is there specific things that we could do?

Dr. ROSE. Yes. I think that is a very important point. To speak on that, we have also looked at that too, and it is the same story that if they get their care at a high-volume center, they actually do as well as people who live within 30 miles of the center. It is really about getting people to the right experts.

I think that some of that is that the cost of them traveling and the cost of them staying locally to get their treatment is all shouldered by the patient, and if there was some sort of cost offset where they could be housed or provided transport that was not out of their own pockets, something that either was covered by insurance or by a government voucher program, then I think that maybe we would see more people willing, but some of it is people just feel comfortable in their communities, and they do not want to come up to the big city. They do not want to deal with traffic, and they do not want to deal with parking, and it is just uncomfortable for them.

Then I think maybe funding outreach satellite clinics where we can go to them—and we are looking at doing that here in UAB going down to the south and out to the west side of the State at least once a month and running pancreas cancer clinics and letting people come to us, instead of having them drive all the way here. I think there are some innovative ways of achieving that.

People who have limited means, it is hard to expect them to travel 5 hours on their own dime to get to see somebody.

Senator JONES. Hillery, you are obviously a businesswoman. Giles was a successful lawyer. You had not only UAB next door; you had the resources that a lot of people do not have. Can you just imagine what it would have been like had you not had those resources?

Ms. HEAD. I cannot, and after spending so much time here at UAB talking to other people, realizing the distances they traveled and the hurdles that they had to go overcome in order to come and get the treatment, it is an overwhelming disease anyway on its own.

Senator JONES. Steve, you mentioned the Department of Defense. I would like to go back to that a little bit. It was one of the issues, one of the things that we tried to get, as you know, in the Senate version and could not quite make it. I do not know where it will end up in our conference with the NDAA, but we are still working.

That Department of Defense, I do not think people fully appreciate the fact that they do some amazing medical research, and what would you like to see in that Department of Defense? You mentioned it briefly, but let us go over it again because this is an

official Senate hearing, and it is on the record for all of my colleagues to see and hear.

Mr. COOK. No pressure.

Mr. COOK. Well, very specifically, we would like to see pancreatic cancer established in its own dedicated research line in a congressionally Directed Medical Research Program for cancer, CDMRP, get a $10 million line for pancreatic cancer in there.

Right now, it has to compete within the broader program, and because of that, again, as we talked about earlier, only about 6 percent make it through that process. That $10 million of funding, we got $6 million in the House line, and so we would like to get it to 10 in the conference process. It is critically important because we are leaving so much research on the table.

Twenty years ago, there was effectively no pancreatic cancer research field. In 1999, there was only a handful of researchers even studying pancreatic cancer. What we found out is that the work that the DoD does is very complementary. Some people say, "Well, why are we funding the DoD?" Number one, it is a complementary program focused on high-risk cancers, fits there. There is a higher incidence rate among our veterans of pancreatic cancer, so it fits there and it is not an overlap of what goes on over at the National Cancer Institute today.

They have done some great programs at DoD. They have been looking at targeting the gene, the KRAS gene, which is a critical one, biomarkers to detect pancreatic cancer earlier, how do we activate the immune system, how do we take advantage of metabolic differences in people, and a lot of other novel therapeutic approaches.

This particular cancer is not going to be—we are not going to get the rates down, I do not personally believe, but with chemotherapy. Almost all the things that were mentioned up here today, they are very difficult. I mean, they are 7-hour sessions, some of them to be every couple of weeks, and it just wipes the person out as you go through that process. It is going to have to be engineered. We have got an engineered solution.

I would kind of simplify it and say it this way. It is very similar to cars driving down the road, and you do not have any brakes, and the pedal is pushes to the floor, but you got to stop the car, and that is what we have to figure out ways to do. Well, there is all kinds of other ways you could stop a car from the outside, and that is the creativity we need to get researches to apply. They are doing it in other areas, but this is one of the toughest cancers to unlock because of the way it is—not just because of its diagnosis issues, but because of the genetics associated with it.

I am an engineer. I have built launch vehicles, and I sent payloads to space. If we can do that as a Country, we can absolutely do this.

Senator JONES. Great. Thank you.

Dr. Rose, anything? We are going to kind of wind up so we can open it up, if anybody in the audience wants to, but do you got any final thoughts, something that we did not cover that you would like to say or do or implore us to do in the Senate or the House?

Dr. ROSE. I think we have, obviously, covered the kind of dearth in funding, and that is a big thing.

I think outreach is, again, very important, and I would like to see kind of a public health campaign stressing the fact that this is not an untreatable and uncurable disease, as many people think. I think, again, there has been multiple studies now and a followup 10 years later that showed that people with potentially curable stage I pancreas cancer, only 40 percent of those people are ever being referred to a surgeon. That is really the chance for a cure there, and it is a huge missed opportunity for a number of patients. There may be any number of reasons for that, but it does not seem to be health-related. It seems to be just this nihilistic thought that this is a death sentence, and I think we just really need to stress that in 2019, that is not always the case. I would like to see more public awareness of that, especially within the medical community.

Senator JONES. All right. Thank you.

Ms. Nall, any final comments?

Ms. NALL. The tumor marker, I know you discussed that a little bit, but I was wondering if that could be part of—you know, we go to get a physical every year. Why not have that part of the CDC or whatever they call it? I think the number was between what? Zero and 35?

Dr. ROSE. For normal.

Ms. NALL. My daughter is way off the chart. If they had done that test, the CA 19–9, the tumor marker, then maybe that would have been an indication, indication to do something different.

Dr. ROSE. That is a wonderful thought. The CA 19–9, which is the tumor marker I think you are talking about is problematic for a number of reasons.

About 10 to 12 percent of people do not even make that marker, and so they could have metastatic or stage IV pancreas cancer, and it would be unmeasurable, which is we cannot use it to track them.

It can be high for reasons that are not cancer. Then that leads to a lot of unnecessary testing and worry.

Then the actual number itself does not really correlate with how bad the disease is. It may not even start getting high until they have already spread, and so for those reasons, it just has not, unfortunately, panned out to be very useful, other than if you have a number and you can watch it on treatment, what happens to it? Is it going up? Is it going down? Then that can give you a sense of how you are responding to treatment and whether or not maybe the tumor is coming back because it was low and now it is going high again. It is useful for tracking it but not for diagnosing it, and we just do not have anything better yet.

Ms. NALL. It should be part of the research.

Dr. ROSE. Absolutely.

Senator JONES. Thank you, Ms. Nall.

Hillery, any final thoughts?

Ms. HEAD. No.

Senator JONES. All right. Well, thank you. I want to thank all of the panelists and witnesses today. It is just an amazing group, an emotional group for all of us.

Committee members—as I said, this is an official Senate Aging Committee hearing. Committee members, other Senators, will have until Monday, November the 25th, to submit additional questions for the record, so it is possible that you could get additional ques-

tions, so we are going to conclude the official part of this hearing so that we can talk to some of you if you are willing to do that.

With that, the hearing is adjourned. Thank you.

[Whereupon, at 10:39 a.m., the Committee was adjourned.]

APPENDIX

Prepared Witness Statements

Testimony to the Senate Special Committee on Aging Field Hearing
"Pancreatic Cancer: Fighting the World's Toughest Cancer in Alabama and Nationally"
November 15, 2019

Hillery Head

Good morning, Senator Jones and members and staff. Thank you for the opportunity to share my family's story. `

My name is Hillery Head, and I am a mother, a business woman, and native Alabamian. I am also a widow from pancreatic cancer.

In the spring of 2016, my husband, Giles Perkins, began feeling under the weather. His health declined rapidly, and none of the antibiotics he took seemed to help. I urged him to see my primary care physician, who ran him through a battery of tests, diagnosed him with Stage 4 Pancreatic Cancer. It was the day before our eldest child graduated from high school.

Of course, we were stunned. The only reason I believed the diagnosis was that it offered an explanation of how Giles had gone from an active and vibrant 48 year old to a jaundiced invalid in a matter of weeks.
Always realists, Giles and I faced the fact that our family had to learn how to live with cancer, quickly. In the same manner we had approached problems throughout our 25 year marriage, we weighed what was in our favor, and what was not.

No doubt, we had a terrible diagnosis.

But we had also a number of things in our favor:

- Giles and I had 3 healthy, sane children,
- Two of our children were old enough to drive and help out
- We had supportive friends and family close by
- University of Alabama Birmingham , a world renowned Comprehensive Cancer Center, was 2 miles from our home
- Dr. Selwyn Vickers, a renowned pancreatic cancer specialist, was at UAB, and helping us
- We both worked jobs that allowed flex time,
- We had very little personal debt
- We had first class health insurance, and we knew it would remain in place throughout the course of the disease.

In many ways, we literally faced this terrible diagnosis with the world in our favor. We were acutely aware of how lucky this was.

And so, we started down the path of living with cancer. Chemo started, and Giles responded well. With our children, we made a conscious decision to live each day as a gift, and not to mourn Giles until he was truly gone from us.
Fighting the disease was very difficult. Chemotherapy is poison, and the effects of the poison (while it drove back the cancer), took away Giles' ability to hear, caused debilitating pain in his legs and hands, and made mobility an issue for a previously active 48 year old.

The stress and trauma of watching Giles battle this illness, took a toll on him, on me, and on our three children. Again, we had the luxury of support, through counselors, spiritual leaders, friends and family. We had the luxury of connection to our children's schools, and to Giles' doctors. People knew what was going on, and people cared.

And so the fight continued, for 3 years. When known chemo stopped working, we moved on to more experimental combinations. And when those did not work, we moved into the stage of managing pain.

"Managing Pain" is a benign term for a terrible situation. The pain was so debilitating that Giles could not think or function without massive amounts of pain medication. For those who do not know, to watch someone you love in pain is suffocating.

Again, we took stock of what was in our favor:

- UAB's palliative care group was 2 miles from our house,
- UAB's palliative care group was available to talk 24/7.
- We hired wonderful caregivers to help Giles while I continued to work.
- Giles could tolerate high doses of pain medication, and he continued to work from home.
- Giles' brain continued to be sharp, his spirits remained high, and he continued to want to live

Despite all that was in our favor, on December 2, 2018, Giles passed away. He died in our home, surrounded by family and friends and people who loved him.
He fought this disease, from beginning to end, with every fiber of his being. He knew, and I knew, how very lucky we were, in the midst of this great misfortune.

And so I leave you with these thoughts:
Cancer doesn't care

- how young you are,
- how educated you are,
- how good your job is,
- how rich you are,
- what your religion is,
- how many marathons you've run,

- how much your children need you.

Cancer doesn't care.

So, it's up to us to care. It's up to us to support, to fight, to fund, to help, to love, and to live every day like it is a gift from God. It's up to us to support families facing this same diagnosis, and find a cure for this disease.

Thank you for listening to my family's story.

Testimony to the Senate Special Committee on Aging Field Hearing

"Pancreatic Cancer: Fighting the World's Toughest Cancer in Alabama and Nationally"

November 15, 2019

Lynette F. Nall

I am Lynette F. Nall.

Letisha was my first-born child, born February 5, 1972. She was a healthy child, growing up only to see a doctor only for annual physical exams each year. As she grew into adulthood, she was still healthy, eating healthy and exercising on a regular basis. She was a devout Christian, married with three (3) children, Kirsten 23, Dexter 21 and Selice 9 years of age. In February, "Tish", as we called her, started having trouble getting comfortable when laying down. She said no matter how she would lie down, she couldn't get comfortable and had trouble sleeping. Tish had light pain in her lower back. She went to see her primary care physician, but he couldn't find anything wrong. She went on with the light suffering for about three (3) months.

In May of 2017, my husband Ronald, Letisha, Kirsten, Selice and myself took Kirsten to Iowa for a summer job and to attend the University of Iowa in August. Tish was still uncomfortable but tolerated the pain. We stayed in Iowa three (3) days. Upon our return back, Tish's pain got a little worse. She got extremely nauseated and we had to stop on the side of the road. The nausea was the worst I had ever seen. We proceeded on the return trip home but stopped at the next exit at CVS and picked up about 3 nausea medications. We made the trip home without another nausea episode.

On June 23, 2017, Tish dropped Selice off at my home as she did every Friday. She didn't look well but said that something she smelled at church made her sick. She said she would go home and rest, but the next call we received was from the St. Vincent's Emergency Room. She drove herself to the hospital. I told my husband go to the hospital and that I would come in the morning to relieve him.

Ronald called later in the night to let me know she would be admitted to the hospital and would be on the oncology floor. THAT was something I did not expect to hear.

A biopsy was performed on June 26, 2017. The diagnosis on June 27 was Pancreatic Cancer, Metastatic Adenocarcinoma, Stage IV, Grade III. All of us were devastated! Dr. Ira Gore was the oncologist assigned to Tish's case. However, she was suffering from mental abuse from her husband, causing her much stress. She moved in with my family until her death in January, 2019.

On July 12, 2017, Dr. Gore started her on a Gemzar and Abraxane cocktail, three weeks on and one off. This treatment regimen lasted through November. Tish had the month off for December, blood counts were low and needed a break from treatment. Her tumor marker (CA-19-9) went from over 80,000 to around 1,000. It was better but far from normal. Tish appeared to be improving, and was sweet, strong spirited and very positive. Her faith was strong!

In January 2018, tumor markers went up again. Tish was also having severe back pain, nausea and constipation. She was also highly fatigued. Meds were used to resolve those issues. Dr. Gore decided to try immunotherapy, Keytruda. The pain worsened with the Keytruda. Pain meds were increased. Keytruda stopped after two treatments. Tish started feeling pain under her rib cage that Dr. Gore contributed to the cancer in the liver.

In March 2018, Dr. Gore changed the treatment to Fluorouracil (5-FU) regimen. This regimen continued through September 2018. By this time, Tish's tumor marker had gone up to over 184,000. She was also extremely tired and weak. Her blood counts were low.

In October 2018, Dr. Gore changed the treatment regimen to (Xeloda) Capecitabine 3000 mg daily, 2 weeks on, I week off. He also referred Tish to Dr. Walid Shaib, Emory Winship Cancer Institute in Atlanta. Dr. Shaib qualified Tish for a trial but wanted to wait and see if the Capecitabine would work. He did state that the Keytruda would have probably worked had she stayed on it longer. Dr. Shaib advised that the Keytruda causes the cancer to swell before it gets better, hence the increase in her pain. Visits to Atlanta were monthly.

In December 2018, Tish was very short of breath. Dr Shaib requested to take her to Emory ER. Tish had fluid on her lungs that had to be drawn off by a pulmonary doctor via a Thoracentesis. This fluid drainage had to be done twice more in January. She also started retaining fluid in her abdomen. She had to have a paracentesis to drain the fluid from her abdomen. Tish was also in intensive care for several days for blood clots on her lungs. She was released in the care of Hospice.

On January 30, 2019, after a few days at home, Tish succumbed to the disease in bed early that morning. Needless to say, there should be early detection for this disease. Tish's first visit to the doctor should have resulted in some test that could have saved her life. With all the trials that have been done, and still going on, there should be some specific treatment that has been proven to work well for this cancer. The trial and error methods were frustrating for Tish, and for me, as her mother, to see her suffer.

TESTIMONY OF
MR. STEVE COOK OF HUNTSVILLE, AL
PANCREATIC CANCER ACTION NETWORK
(PanCAN)

TO THE SENATE SELECT COMMITTEE ON AGING
FIELD HEARING
"PANCREATIC CANCER: FIGHTING THE WORLD'S TOUGHEST CANCER IN ALABAMA AND NATIONALLY"

BIRMINGHAM, AL
NOVEMBER 15, 2019

Senator Jones, on behalf of the Pancreatic Cancer Action Network, PanCAN, I want to thank you for convening this field hearing today to highlight pancreatic cancer and the importance of federal support for pancreatic cancer research. My name is Steve Cook and I am your constituent. I am here today because my first wife Marqueta died from pancreatic cancer and I am also representing the entire pancreatic cancer community, including pancreatic cancer patients, families and researchers from across the country. PanCAN is a leading patient advocacy organization focused on pancreatic cancer with a goal to dramatically improve patient outcomes.

When Marqueta was diagnosed with stage IV pancreatic cancer in June of 2017, my family and I were dumfounded. We quickly realized this was going to be the fight of her life. As an engineer – I like to solve problems and I knew I needed to learn more about this terrible disease, so I reached out to several resources, including PanCAN. As she continued to battle the disease, and we began learning more about pancreatic cancer, I realized that funding for research was a challenge. Recognizing that one of the strongest weapons we have in fighting the disease is federal research funding, Marqueta encouraged me to take the message to our leaders in Washington, D.C. I attended my first PanCAN Advocacy Day in 2018, about two weeks after she passed away, just 12 months after her initial diagnosis. Truth be told, I considered not going but I knew she had wanted me to go – I am very glad I did. This disease can render you hopeless but taking a unified message to Capitol Hill with hundreds of others was inspiring – we all had a shared bond.

My story is unfortunately far too common – 65% of patients die in their first year of diagnosis. This year alone nearly 57,000 Americans will be diagnosed with pancreatic cancer, including an estimated 910 from Alabama. Pancreatic cancer is currently the third leading cause of cancer-related death in the United States and expected to become the second leading cause of cancer death by 2030. While survival rates for many other cancers have improved, the five-year survival rate for pancreatic cancer is only nine percent. That means that of 100 people that are diagnosed today, only 9 will

still be alive in 5 years. These statistics are unacceptable. There is no early detection strategy for pancreatic cancer and few effective treatment options. We must demand better and research funding is the key to solving this challenging disease and changing these devasting statistics.

Thanks in large part to the step Congress took in addressing pancreatic cancer through the Recalcitrant Cancer Research Act of 2012, the National Cancer Institute is making progress implementing the bill and providing new research opportunities for pancreatic cancer. And while there has been a slow increase in the federal investment in pancreatic cancer, research funding remains disproportionate to the severity of the disease.

Along with the NCI, the Department of Defense (DoD) is an important source of funding for cancer research. The DoD focuses on high risk, high reward research, an important compliment to NCI research funding and critically important for a disease like pancreatic cancer. Research shows that within a cohort of U.S. veterans, there is a direct evidence for increased risk of death from pancreatic cancer. Veterans often have known risk factors for pancreatic cancer, including environmental exposure, other medical conditions such as diabetes, and lifestyle factors such as smoking and obesity.

Thanks to you and your colleagues, since 2011 Congress has provided funding annually for pancreatic cancer research through the Peer Reviewed Cancer Research Program (PRCRP) at the DoD. This funding has provided a small but important amount of support for innovative and competitive pancreatic cancer research. However, through the highly-competitive PRCRP mechanism, each year there are upwards of a dozen other cancers that are eligible for funding. Only a few pancreatic grants are awarded each year. In fact, in fiscal year 2018, 80 pancreatic cancer grant applications were submitted to the PRCRP, but only 5 were recommended for funding.

A more focused pancreatic cancer research effort at the DoD is desperately needed. We believe a positive step forward is the creation of a new, dedicated DoD research program for pancreatic cancer. Earlier this year, 102 Representatives sent a bipartisan letter to the House Appropriations Committee requesting a $10 million pancreatic cancer research program in the fiscal year 2020 Defense Appropriations Act. Senator Jones, you joined 24 of your Senate colleagues in signing a similar letter to the Senate Appropriations Committee urging the committee to create a new Pancreatic Cancer Research Program. I am extremely appreciative of your support and leadership on behalf of this request.

In June, the House took an important step when it approved its version of the fiscal year 2020 Defense Appropriations Act. Thanks to the bipartisan leadership of Representatives Anna Eshoo and David McKinley, the House bill includes $6 million for a new dedicated Pancreatic Cancer Research Program. Unfortunately, the Senate version of the bill marked up by the Senate Appropriations Committee in September does <u>not</u> include any funding for a new pancreatic cancer program. In the Senate bill, the disease remains in the PRCRP – competing with other diseases for research

dollars. As a result, due to the complicated budget situation, it appears that our best approach moving forward is to increase the House-approved amount to $10 million in the final conferenced version of the Defense Appropriations Act. PanCAN hopes that you will continue to champion this request and work with your colleagues on the House and Senate Appropriations Committees to make sure the new Pancreatic Cancer Research Program is funded at $10 million.

Pancreatic Cancer does not discriminate. Notable figures have recently been in the news like Alex Trebek, the host of JEOPARDY and Supreme Court Justice Ruth Bader Ginsberg. This also isn't a blue or a red issue, it's literally a purple issue. I found myself praying in the office of a senator with differing political views than me. Because as I noted earlier, going through this disease bonds you with others – you become a part of a community, a community that's committed to saving lives. And that's why I am here today. The time is now.

Senator Jones, on behalf of PanCAN and the thousands of American families who, like me, have lost a loved one to pancreatic cancer, I want to thank you again for holding this hearing today. We look forward to continuing to work with you to change the lives of those in Alabama, across our country, and around the world who have been diagnosed with this deadly cancer.

UAB MEDICINE

November 15th, 2019

Report on the State of Pancreatic Adenocarcinoma in 2019

Presented by J. Bart Rose, MD, MAS to the congressional hearing on pancreatic adenocarcinoma chaired by Senator Doug Jones.

Thank you for this opportunity to testify regarding the state of pancreatic adenocarcinoma medical care in the United States in 2019. Pancreatic adenocarcinoma is a leading cause of cancer related death in the United States. It is the fourth most common of cancer related death and is projected to be the second most common by the year 2020 due to a rising incidence of nearly 2-3% per year in the last decade. We have seen, unfortunately, a stagnant rate of 5 year survival of 9%. This is due in large part to the fact half of the patients that are diagnosed with pancreatic adenocarcinoma will already have stage IV (i.e. metastatic) disease at their initial visit. At this time, we have very limited resources to treat this advanced disease and most patients succumb to the cancer. Within in the state of Alabama, we predict 910 new cases of pancreas cancer in 2019 and unfortunately 770 cancer related deaths. Alabama has a higher death rate from pancreas cancer than would be predicted. Our state has the 9th highest pancreatic cancer death rate in the United States even though it only ranks as the 21st highest rate for new case numbers. Among the healthcare workers who have the privilege of helping patients with pancreas cancer, improving survival from pancreas cancer is our top priority. The poor survival in Alabama compared to other states may be due to disparities in cancer outcomes seen between Caucasian Americans and African Americans. We know that an African American with pancreas cancer has up to a 3% increased risk of death over a Caucasian patient. Since African Americans comprise approximately 27% of Alabamians, our state is more diverse than most others which means that this difference in pancreas cancer survival is compounded compared to other more Northern states with less African American representation. We know that of the 25% of patients who are eligible for an operation to remove their pancreas cancer, only 40% are ever offered this potentially lifesaving operation. This is a huge opportunity to help Alabamians with pancreas cancer, as surgery is the only option for cure. This disparity in access to life saving operations are even worse in African Americans.

To make any significant impact in the survival for this devastating disease, we need to address a number of deficiencies in its care.

1) As the majority of patients will present with pancreas cancer that cannot be removed, we need both better treatments for advanced stage disease and ability to detect disease at an earlier stage. Both of these require investment in medical research. In 2019, the National Cancer Institute (NCI) was budgeted by Congress $6.1 billion. While seemingly an improvement over prior years, when adjusted for inflation has been stagnant for over a decade. Only $221 million dollars or approximately 4% of the NCI budget was awarded to study pancreatic cancer, the 4th leading cause of cancer related death. Private society funding is also limited for research in this disease compared to other cancers of higher incidence. As a pancreatic cancer researcher, I can state without question that investment in this area is desperately needed. The only way we are going to move the needle on improving overall survival beyond the currently unacceptable 9% is by having better therapy for advance disease and earlier detection.

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2) We need to improve our outreach efforts into the community and encourage patients to be seen by qualified surgeons to discuss potentially lifesaving operations. As a medical community we need to break the unfortunately nihilistic perception of pancreas cancer, and spread our message of hope. Primary care providers need to be informed that this can be a curable disease.
3) We need to address disparities within health care including those within pancreatic cancer. In the Deep South where we celebrate our diversity with a large proportion of African Americans, this disparity is particularly relevant. Additional money should be made available to study and reverse these disparities.

At The University of Alabama in Birmingham, we are trying to address many of these above stated issues. We have a number of basic and translational science projects dedicated to advancing the study of this disease as well as focusing on dipartites present in the Deep South population. We are the largest treatment center in this region for pancreatic cancer and are focused on providing modern multi-disciplinary care through our dedicated Pancreatobiliary Disease Center.

I would like to again thank the committee for the opportunity to provide this testimony.

Sincerely,

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