

Social Security Administration
Compassionate Allowance Outreach Hearing on Cancers
Monday, April 7, 2008

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Commissioner Astrue, members of the esteemed panel, fellow panel members, and guests:

I am honored to speak to you today on behalf of the Pancreatic Cancer Action Network, a nationwide advocacy organization dedicated to working together to advance research, support patients, and create hope for those affected by pancreatic cancer.

This year, approximately 37,680 Americans will be told that they have pancreatic cancer. The majority will be told that they have fewer than six months to put their affairs in order, and that little can be done except to make them comfortable. And so will begin their journey into trying to figure out how to close out a life in less than six months while managing the extreme pain and complications that generally come with a diagnosis of pancreatic cancer.

Unfortunately, the bottom line for pancreatic cancer patients has not significantly changed in the last 30 years. It is still a death sentence for the majority of those diagnosed. To make matters worse, it is a death sentence that will be realized quickly, and with great pain. Seventy-five percent of patients die within the first year of diagnosis. In fact, the average time from diagnosis to death is a mere 4-6 months. Ninety-five percent of patients die before reaching the 5 year survival mark.

Part of the problem is that there is currently no standard diagnostic tool. One of the most common early symptoms is innocuous – lower back pain. For an otherwise healthy adult, pancreatic cancer is generally the furthest thing from a physician's mind. Indeed, many of those finally diagnosed with pancreatic cancer are subjected to a number of tests and false diagnoses before receiving the news that the true culprit is their worst nightmare. Diagnosis is made more quickly when a patient presents jaundiced, but the trade-off is that the jaundice signifies that the tumor has invaded or blocked the bile-duct and that the disease is too advanced at this point to be treated successfully with the only measure that can make a difference for pancreatic cancer patients, the Whipple surgery.

Some of the tools that are currently used for diagnosis include: CT, Endoscopic Ultrasound (EUS), PET scan, Endoscopic Retrograde Cholangiopancreatography (ERCP), MRI, and a blood test, the CA 19-9 Radioimmunoassay. There are problems with each of these tools. In fact, research into diagnostic tools is a top priority for the Pancreatic Cancer Action Network. While there is some evidence that EUS is the best method for detecting small lesions, this test does not pick up metastasis. A further problem is that few pancreatic cancer cases are diagnosed at these early stages.

There are also no effective therapies to treat or manage pancreatic cancer. Only a few patients whose disease is caught early enough can truly have hope that their disease can be successfully managed through the Whipple, a complicated surgical procedure. At most, only 15% of pancreatic cancer cases are caught early enough for surgery. The surgery is generally followed by chemotherapy or chemotherapy with radiation. Even for patients who qualify for this complicated surgery, there is little chance of long-term survival. Most will have a recurrence within 2 years and less than 20% will survive more than 5 years.

Once the tumor has spread into surrounding tissue or local organs and cannot be removed by surgery, treatment becomes focused on control of the disease and palliative care with a chance for increased survival. Approximately 26% of patients are diagnosed at this stage. Only 8% of them will survive more than 5 years.

The majority of patients – 52% – are diagnosed with late stage pancreatic cancer that has spread to distant organs or sites. The goal of treatment in this case is palliative care. Only 2% who are diagnosed at this stage will survive for more than 5 years.

As I mentioned earlier, a diagnosis of pancreatic cancer is a death sentence for at least 95% of the patients diagnosed and 75% of patients will die within the first year. The majority of patients have a mere 4-6 months to come to terms with their disease, put their affairs in order, and say goodbye to their loved ones. Treating pancreatic cancer can be very expensive as therapies are costly (Tarceva is approximately \$3,800 per month) and many patients require home health care and are faced with additional expenses related to the high cost of end-of-life care. For those who are diagnosed while they are still in the midst of their careers, the disease is particularly cruel as expenses quickly mount and options for assisting their families are few and far between.

We are also deeply concerned that the incidence of pancreatic cancer will continue to climb as our population ages and more baby boomers are diagnosed. Further, we know that there are links between diabetes and pancreatic cancer. While we still have much to learn about the nature of the links, we are mindful that this connection could also cause a spike in pancreatic cancer diagnosis.

Compassionate allowances could be helpful to pancreatic cancer patients, provided that the determinations are made with the utmost speed. The reality is that one month is probably too long for these patients to wait and the current standard of having to wait 45 days or more for a determination and then another 5 months to receive benefits puts compassionate allowances beyond the reach of most pancreatic cancer patients. Time is a luxury they simply do not have.

I will be glad to answer any questions you have, and thank you for the opportunity to present this testimony.