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Testimony before the Health Subcommittee of the House Energy and Commerce Committee

“NCI Cancer Research: Today’s Progress; Tomorrow’s Challenges”

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Members of the Subcommittee, I want to thank you for the opportunity to testify at today's hearing, "NCI Cancer Research: Today's Progress; Tomorrow's Challenges."

My name is Kristin Fitzgerald. As a former health staffer for Representatives John Boehner, Judy Biggert, and Harris Fawell, I have participated in many Congressional Hearings. This is however, my first time on this side of the dais, and I greatly appreciate the opportunity to speak to the challenges facing cancer research.

I am here today not only on my own behalf, but that of my husband, Ray Fitzgerald.

Ray was also a Congressional staffer. In fact, he worked for six years as legislative director for the Ranking Member of this Commerce Health Subcommittee, Congressman John Shimkus.

Ray died last January of gastric or stomach cancer.

Until his diagnosis in May of 2008, Ray was a healthy 36 year old man. He had no risk factors for cancer. He had never smoked, drank infrequently and lived a healthy lifestyle. With 12 aunts and uncles and 72 first cousins in his large Irish family, there were only four unrelated incidences of cancer before him. Nothing would ever have put him at high risk of a cancer diagnosis.

Ray's cancer symptom was burping which appeared for a period of two months before his cancer was diagnosed.

When Ray was diagnosed, his cancer was an advanced stage IV. His gastric tumor had spread throughout the lining of his stomach and progressed to his esophagus and liver.

We were told that there was no hope of a cure but that chemotherapy could reduce the cancer for a time.

That time was eight months.

This is not an abnormal scenario for gastric cancer, it is the second deadliest cancer worldwide. It very often presents in Stage IV, and is always incurable at that point.

Ray however, was forty years younger than the average gastric cancer patient, and thus the grim prognosis impacted not just Ray, but myself and our three young daughters, Nora (5), Maggie (3) and Lucy (1).

Members of the Subcommittee, it is my belief that Ray's diagnosis and prognosis is our worst cancer nightmare: diagnosis of a *deadly cancer* at an *advanced stage* where a *cure is impossible*. It is a death sentence.

And if we think it can't or won't happen to us, we are wrong. Ray was you -- or at least, your staff. And as I have learned, it could even be happening to one of us right now, and we would never know it.

After Ray died I spent time talking with Ray's doctors to see how this kind of scenario can be prevented so that more young dads and moms aren't violently stolen from their families by cancer.

As a former health staffer, I assumed that gastric cancer research was ongoing and would utilize Ray's tumor specimen and facts about his age and health status to find a cure for this deadly cancer.

However, far too little is being done to research gastric cancer and other gastrointestinal cancers that have a similar deadly prognosis. CBS news analyzed the disparity in research dollars in May of 2009. For every cancer death, the most federal research dollars were spent on cancer of the cervix (\$18,870) and breast (\$14,095) and on Hodgkin lymphoma (\$12,791). The least funded was gastric cancer (\$1,168), with esophageal cancer a close third at (\$1,542).ⁱ

Gastrointestinal (GI) cancers are some of the deadliest cancers in the U.S. with deaths attributed to the digestive system second only to those in the respiratory system. Four out of the five lowest five year cancer survival rates for metastatic cancer are GI: Pancreas 1.7%; Liver 2.8%; Esophagus 2.9% and Stomach 3.4%.ⁱⁱ

And, gastrointestinal cancers are rising, particularly in young people. Though it is very difficult to track current trends in cancers in a timely way because of the slow reporting of Surveillance Epidemiology and End Results (SEER) data, a recent NCI article documented the rise in gastroesophageal cancers of the stomach and esophagus. The article compared the incidence rates in two four year periods, 1975-1979 and 2000-2004. Overall there was a 44 percent increase in these cancers. Within gastroesophageal cancers there was an explosion of a particular type, adenocarcinoma. The increase in adenocarcinoma was 465 percent, with an 190 percent increase in young white males.ⁱⁱⁱ Attachment 1

And the situation for young people with GI cancers is particularly grim. Because GI cancers are considered to be diseases of middle or advanced age, the diagnosis of GI cancers in people under 40 is often delayed. As a result, the disease is usually in an advanced stage with a poor prognosis by the time the diagnosis is established. And their very age works against them as the strength and relative health of their bodies is passed on to their cancers making them even more aggressive than in older patients. As a result of the delay in diagnosis and the more aggressive phenotype of cancers in young people, GI cancers in young people tend to be fatal.

Yet, unlike other deadly cancers, gastric cancer and many other gastrointestinal cancers do not have a national clinical registry and tissue bank, to utilize tumor tissue and clinical records for research purposes.

In my view, this is intolerable. Congress and the National Cancer Institute can and should do more to ensure that researchers can have access to the tools they need to prevent and diagnose these cancers before it is too late.

Though these cancers are growing, they are poor candidates for wide-scale screening programs due to the smaller population of people impacted and the invasive nature of screening available.

More research is *essential* in order to understand the unique characteristics of the disease in younger people and develop a *screening test based on molecular markers to allow for earlier detection*. In order to accomplish this research, the National Cancer Institute must also develop a coordinated national GI cancer tissue biorepository, and accompanying research project to focus research in this area and make tumor tissue available for research purposes.

Last year the Labor, HHS, and Education Appropriations Report included language asking the National Cancer Institute to develop a research project and accompanying tissue repository to study GI cancers in young people. To date, this has not been accomplished.

Congress must act to ensure that these cancers can be detected and cured so that more lives are not lost.

Ray was a wonderful man and the legacy of his *spirit* will live on always. However, it is my belief that Congress should fund a research project, tissue bank and registry so that the *physical legacy* of patients like Ray can *live on forever, giving eternal gifts to researchers and scientists throughout the world*.

Members of the Subcommittee thank you for your time and consideration. I am happy to answer any questions.

ⁱ Data compiled and reported by CBS Evening News, May 27, 2009.

ⁱⁱ American Cancer Society. Cancer Facts & Figures 2008. Atlanta: American Cancer Society; 2008.

ⁱⁱⁱ "Incidence of Adenocarcinoma of the Esophagus Among White Americans by Sex, Stage, and Age," Linda Morris Brown , Susan S. Devesa , Wong-Ho Chow, Journal of the National Cancer Institute 2008;100: 1184 – 1187.