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Labor-HHS-Education Appropriations Subcommittee

Public Witness Hearing on FY 2011 Appropriations

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Testimony concerning FY 2011 Funding at the Department of Health and Human Services for Programs Related to Gastric (Stomach) Cancer and other Gastrointestinal Cancers (GI) in young people at the National Cancer Institute and the National Institutes of Health

Members of the Subcommittee, I want to thank you for the opportunity to testify at today's public witness hearing on FY2011 funding for the Labor, Health and Human Services and Education Appropriations Act.

My name is Kristin Fitzgerald. As a former health staffer for Representatives John Boehner, Judy Biggert, and Harris Fawell, I know the work involved in Congressional Hearings. Thus, I particularly appreciate the opportunity to speak to the Subcommittee today on the dramatic need for funding to research gastric (stomach) cancer and other gastrointestinal (GI) cancers in young people.

I am here today not only on my own behalf, but that of my three young daughters, all of whom miss their father, my husband, Ray Fitzgerald, who died last year of gastric or stomach cancer.

Ray was also a Congressional staffer. He worked for six years as legislative director for Congressman John Shimkus of Illinois.

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 a very 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. Let me be clear, the time between diagnosis and Ray's death was only 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, at 36, 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* with very few warning symptoms 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 treatments and cures.

However, far too little is being done to research gastric cancer and other GI 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]

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] These four GI cancers make up half of the eight most deadly cancers which together account for almost half of the United States' cancer deaths.[iii] Yet, research to treat and cure these cancers accounts for a vastly disproportionate percentage of NCI's funding. Attachment 1

And, GI cancers are rising, particularly in young people. Just last week, the National Cancer Institute (NCI) released a study based on surveillance tracking of gastric cancer. Gastric cancer was declining in every age range except age 25-39. There, one's likelihood of being diagnosed with gastric cancer has increased dramatically by almost 70 percent since 1977.[iv]

Likewise, 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 type Ray had. The increase in adenocarcinoma was 465 percent, with an 190 percent increase in young white males.[v]

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 GI 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 NCI 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, NCI must 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. *A specific research project is extremely important* as difficulties in obtaining tumor tissue, make a specific research project important in order to obtain Institutional Review Board (IRB) approval to go beyond the standard of care in obtaining tumor tissue.

Last year the Labor, HHS, and Education Appropriations Report included language asking the NCI to develop a research project and accompanying tissue repository to study GI cancers in young people.

Language for FY 2011 asking NCI to report on its progress to the Subcommittee has been submitted by Congressman Jesse Jackson, Jr.

After my testimony to the House Energy and Commerce Health Subcommittee on the increase of these deadly cancers in young people, work with NCI has commenced to develop alternative

appropriations language for FY2011 to include gastric cancer in the Cancer Genome Atlas and set forth projects to study gastric cancer, but research projects have not yet begun.

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.

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[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] Deadly Cancer Coalition. The Deadliest Cancers. Washington, D.C.: 2010.

[iv] "Age-Specific Trends in Incidence of Noncardia Gastric Cancer in US Adults," William F. Anderson, MD; M. Constanza Camargo, MSc; Joseph F. Fraumeni Jr, MD; Pelayo Correa, MD; Philip S. Rosenberg, PhD; Charles S. Rabkin, MD, Journal of the American Medical Association, May 5, 2010; 303(17):1723-1728.

[v] "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.