

Congress of the United States
House of Representatives
Washington, DC 20515-5401

September 15, 2011

Dr. Francis S. Collins
Director
National Institutes of Health
Department of Health and Human Services
1 Center Drive
Bethesda, MD 20892

Dr. Thomas R. Frieden
Director
Centers for Disease Control and Prevention
Department of Health and Human Services
1600 Clifton Road NE
Atlanta, GA 30333

Dear Dr. Collins and Dr. Frieden:

Recently, I sought to obtain information on cancer in Puerto Rico, including Island-specific data on the prevalence of the disease, the number of new cases annually, the most common forms of cancer, and the number of cancer-related deaths each year. I was disappointed to learn that, while the National Cancer Institute (NCI), the Centers for Disease Control and Prevention (CDC), the North American Association of Central Cancer Registries (NAACCR), and the American Cancer Society (ACS) publish detailed national cancer statistics that are disaggregated for each of the 50 states and the District of Columbia, they publish little if any useful data for Puerto Rico, a U.S. jurisdiction that participates in all major federal health care programs and is home to over 3.7 million American citizens. I respectfully request that you make concerted efforts—in coordination with the Puerto Rico Central Cancer Registry—to begin publishing this information without delay. The goal should be twofold: to collect and publish the same jurisdiction-specific cancer information for Puerto Rico that is already published for the 50 states and D.C., and to include that Puerto Rico-specific information in all national cancer totals. If you identify obstacles to achieving either of these objectives, I ask that you please inform me so that we can work to overcome them.

After heart disease, cancer is the leading cause of death in the United States. Statistical information about cancer is critical to the fight against the disease: it helps policymakers allocate resources, scientists conduct relevant research, and medical professionals advise patients. Accordingly, the absence of Puerto Rico-specific information from national databases and reports published by your agencies has significant adverse health consequences for Island residents. It is an urgent problem that must be remedied.

The U.S. Department of Health and Human Services provide funding to help jurisdictions operate cancer registries that collect population-based data. Specifically, through its National Program of Cancer Registries (NPCR), the CDC—according to its website—supports “central cancer registries in 45 states, the District of Columbia, *Puerto Rico*, and the U.S. Pacific Island Jurisdictions.” (emphasis added). Puerto Rico received over \$550,000 in NPCR funding in FY 2011, and over \$600,000 annually between FY 2007 and FY 2010.

In addition, through its Surveillance, Epidemiology, and End Results (SEER) program, the NCI provides funding to support cancer registries in 10 states, several metropolitan or rural areas within states, and for Alaska Natives, Arizona Indians, and the Cherokee Nation. Cancer statistics for Puerto Rico are not currently collected under the SEER program. Several state cancer registries receive federal funding under both the NPCR and SEER programs.

One important function of state cancer registries is to provide cancer-related data to the federal government and non-profit organizations for compilation and publication. After all, collected data is of little use unless it is published in a format that can be easily accessed by—and shared among—federal and local policymakers, researchers, medical professionals and patients.

For nearly a decade, the CDC and the NCI have combined their data to annually produce the *United States Cancer Statistics (USCS)*, which is the official publication of federal government cancer statistics. The USCS is produced in collaboration with NAACCR, a non-profit organization that collects data provided by dues-paying central cancer registries throughout the nation. The USCS website contains comprehensive cancer data—dating back to 1999—on incidence and deaths rates nationally, by cancer type, and by gender and race. Moreover, much of this data is available for individual states and D.C., although information within certain statistical categories is not always available for certain jurisdictions in certain years. Puerto Rico, by contrast, is completely excluded: no jurisdiction-specific information is provided at all, and the Island is not included in any national totals.

The USCS website also contains a drop-down menu that provides further historic cancer statistics by jurisdiction: the ten most prevalent cancers in that jurisdiction; that jurisdiction’s prevalence rates of specified cancers versus the national rates; and a ranking of those jurisdictions with the highest incidence of specified cancers. Information for every state and D.C.—along with several metropolitan areas—is made available. Again, Puerto Rico is excluded entirely. Indeed, the various other statistical products on cancer that are published by the CDC and NCI, apart from the USCS, appear to contain no relevant information for Puerto Rico.

Beyond its exclusion from official federal government statistics on cancer, Puerto Rico is also excluded from databases published by the NAACCR, which serves as a prime data source for government agencies and cancer-related organizations, including the American Cancer Society.

As a result, Puerto Rico is not included in otherwise useful ACS reports, such as its annual publication “Cancer Facts & Figures”—which contains data disaggregated by state—and its periodic publication “Cancer Facts & Figures for Hispanics and Latinos.”

I hope you share my view that the status quo is untenable. I understand that data provided by a jurisdiction’s cancer registry will not be published by the CDC, the NCI or the NAACR unless it meets certain specified criteria to ensure its reliability and accuracy. If the Puerto Rico Central Cancer Registry—responsibility for which has been delegated by the Puerto Rico Department of Health to the highly-respected, NCI-accredited Puerto Rico Cancer Center, located at the University of Puerto Rico’s Medical Sciences Campus—needs to provide more or different data to your agencies, it is critical that we work together to ensure that it is able to do so. If additional federal resources or technical assistance is necessary to accomplish this goal, I urge that it be provided in a timely manner.

At your earliest convenience, I respectfully request a briefing on the steps your agency can take to help rectify this problem, and that you identify any perceived impediments to those steps.

Sincerely,



Pedro R. Pierluisi
Member of Congress

cc: Dr. Harold Varmus, Director, National Cancer Institute, National Institutes of Health
Dr. Marcus Plescia, Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention, Centers for Disease Control and Prevention
Betsy Kohler, Executive Director, North American Association of Central Cancer Registries, Inc.
John R. Seffrin, Chief Executive Officer, American Cancer Society
Dr. Jaime Torres, Director, Region II, U.S. Department of Health and Human Services
Dr. Lorenzo González-Feliciano, Secretary, Puerto Rico Department of Health
Margaret Wolfe, Assistant Secretary for Family Health, Integrated Services and Health Promotion, Puerto Rico Department of Health
Dr. Nayda Figueroa, Director, Puerto Rico Central Cancer Registry