



INTERNATIONAL SOCIETY FOR ENVIRONMENTAL EPIDEMIOLOGY

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Francine Laden, Sc.D., *President*
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February 24, 2015

The Honorable Suzanne Bonamici
Ranking Member, Subcommittee on Environment
Committee on Science, Space and Technology
United States House of Representatives
Washington, DC

Dear Representative Bonamici:

As the 114th Congress gets underway and your Committee considers its work ahead, I am writing on behalf of the International Society for Environmental Epidemiology to respectfully request a reevaluation of previously introduced and House-passed legislation regarding access to research data.

Last November, the House of Representatives passed H.R. 4012, the Secret Science Reform Act of 2014, a bill that our Society strongly opposed. Had it become law, H.R. 4012 would have prevented the EPA from proposing, finalizing, or disseminating regulations or assessments unless all underlying data were reproducible and made publicly available. In so doing, the legislation would have barred EPA from considering much of the best available science investigating the effects of the chemical, physical and microbial environment on human health, because many of the related findings are based on confidential data, such as private medical information. Neither H.R. 4012, nor its companion, S. 2613, were considered in the Senate.

Our members support the sharing of epidemiological data when its purpose is to advance scientific knowledge and when data sharing protects the confidentiality of study subjects. We have participated in some of the largest data sharing efforts to advance scientific knowledge, and our Society has promulgated transparent procedures that protect patient confidentiality for assuring unbiased reanalysis of epidemiological data sets. Moreover, our members are developing and have applied new approaches to data sharing that both increase transparency and protect confidential information, with the objective of promoting rigorous evaluation of study results by other analysts.

We would welcome the opportunity to discuss our work with you and how we are sharing data for reanalysis and the advancement of science, while also protecting subjects' confidentiality. Furthermore, should legislation similar to H.R. 4012 and S. 2613 be introduced in the 114th Congress, we would appreciate the opportunity to share our strong concerns over the bill's likely impact on the privacy of individual study participants and on the scientific enterprise and human health.

The International Society for Environmental Epidemiology is an international organization with members from more than 60 countries. Topics addressed by ISEE members include environmental exposures, health effects, methodology, environment-gene interactions, and ethics and law. We thank you for your time and look forward to working with Congress in the future.

Sincerely,

A handwritten signature in black ink that reads "Francine Laden". The signature is written in a cursive, flowing style.

Francine Laden, Sc.D.
President, International Society for Environmental Epidemiology

cc: The Honorable James Inhofe, United States Senate
The Honorable Barbara Boxer, United States Senate
The Honorable Lamar Smith, United States House of Representatives
The Honorable Jim Bridenstine, United States House of Representatives
The Honorable Eddie Bernice Johnson, United States House of Representatives
Dr. John Holdren, Director, OSTP