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Charge to the Board of Scientific Counselors

Firefighter Registry Subcommittee

24 September 2019

The Firefighter Cancer Registry Act of 2018 (“Act”) requires that the Secretary of the Department of Health and Human Services, acting through the Director of the Centers for Disease Control and Prevention, and in coordination with other agencies as the Secretary determines appropriate,¹ shall develop and maintain a voluntary registry of firefighters (referred as the Firefighter Registry) to collect relevant health and occupational information of such firefighters for purposes of determining cancer incidence. *See* Attachment.

The Act requires that the Secretary consult with relevant stakeholders as follows: (1) public health experts with experience in developing and maintaining cancer registries; (2) epidemiologists with experience in studying cancer incidence; (3) clinicians with experience in diagnosing and treating cancer incidence; (4) active and retired volunteer, paid-on-call, and career firefighters as well as relevant national fire and emergency response organizations; (5) state health agencies; and (6) State departments of homeland security. *See* Sections 2(d) and (e)

I charge the NIOSH Board of Scientific Counselors to develop a subcommittee with two co-chairs from the BSC at large² to provide professional input to the BSC that will assist the BSC in advising the Director about NIOSH’s efforts to establish and operate the NIOSH Firefighter Registry.

Specifically, I would like the BSC to advise the Director about the following issues pertaining to the “required strategy” (*see* Section (d)(1)) as required by the Act:

(A) Increasing awareness of the Firefighter Registry and encouraging participation among volunteer, paid-on-call, and career firefighters. *See* Section (2)(d)(1)(A).

(B) Consideration of unique data collection needs that may arise to generate a statistically reliable representation of minority, female, and volunteer firefighters, including methods, as needed, to encourage participation from such populations. *See* Section (2)(d)(1)(B).

¹ Delegation from the HHS Secretary, through the CDC Director, to the NIOSH Director is pending.

² Based on the knowledge and expertise of the BSC membership, I have asked Grace LeMasters, Ph.D. of the University of Cincinnati, and Patrick Morrison of the International Association of FireFighters to serve as Co-Chairs of the BSC Fire Fighter Registry Subcommittee.

(C) Information on how the Secretary will store data described in subsection (c)(1) and provide electronic access to relevant health information described in subsection (2)(d)(1)(C). *See* Section (d)(1)(C).

(D) Working in consultation with the experts described in subsection (e), develop a reliable and standardized method for estimating the number of fire incidents attended by a firefighter as well as the type of fire incident so attended in the case such firefighter is unable to provide such information. *See* Section (2)(d)(1)(D).

In addition, I would like the BSC to advise the Director about the following issues pertaining to the “guidance for inclusion and maintenance of data on firefighters” (*see* Section (d)(3)) as required by the Act:

(A) How new information about firefighters will be submitted to the Firefighter Registry for inclusion. *See* Section (3)(A).

(B) How information about firefighters will be maintained and updated in the Firefighter Registry over time. *See* Section (3)(B).

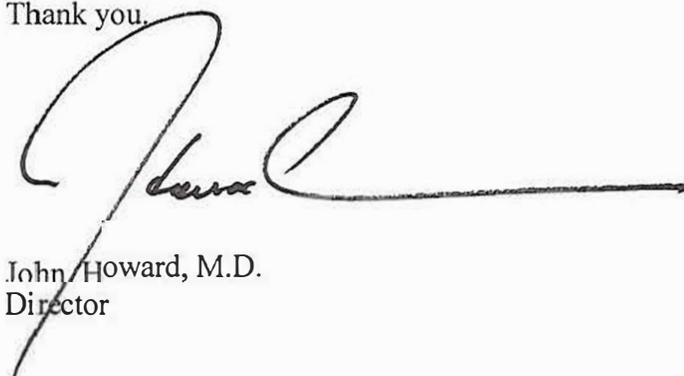
(C) A method for estimating the number of fire incidents attended by a firefighter as well as the type of fire incident so attended in the case such firefighter is unable to provide such information. *See* Section (3)(C).

(D) Further information, as deemed necessary by the Secretary. *See* Section (3)(D).

NIOSH will provide staffing support for the Firefighter Registry Subcommittee. The contact person is CDR Kenneth Fent, Ph.D., CIH, from the NIOSH Division of Field Studies and Engineering.

I charge the Subcommittee to meet at least once per year via a face-to-face meeting, and via teleconference at the discretion of the Subcommittee Co-Chairs and based on the availability of funds.

Thank you.

A handwritten signature in black ink, appearing to read "John Howard", with a long horizontal flourish extending to the right.

John Howard, M.D.
Director