

**Congress of the United States**  
**Washington, DC 20515**

December 21, 2016

Dr. John Howard  
Director  
National Institute for Occupational Safety and Health  
Patriots Plaza 1  
395 E Street, SW, Suite 9200  
Washington, DC 20201

Mr. James Macrae  
Acting Administrator  
Health Resources and Services Administration  
U.S. Department of Health and Human Services  
5600 Fishers Lane  
Rockville, MD 20857

Mr. Leonard J. Howie, III  
Director  
Office of Workers' Compensation Programs  
U.S. Department of Labor  
200 Constitution Ave, NW  
Washington, DC 20010

Dear Dr. Howard, Mr. Macrae and Mr. Howie:

We are writing to request an estimate of the number of cases of progressive massive fibrosis (PMF) and other forms of advanced pneumoconiosis diagnosed among active and former coal miners in the U.S. over the past 5 years, and ask that you continue to assess this on a prospective basis. It is our larger goal to understand the full dimensions and potential burden of PMF and coal workers' pneumoconiosis diagnosed among current and former coal miners, particularly with regards to the impacts on the Black Lung Disability Trust Fund.

Recent investigative reporting by National Public Radio indicates that the number of PMF cases among current and former coal miners is at least 10 times greater than had been previously reported for current miners by the National Institute for Occupational Safety and Health (NIOSH).

Presently, NIOSH conducts screening through its Coal Workers' Health Surveillance Program (CWHSP), which offers active coal miners no-cost medical monitoring that includes a chest x-ray at entry into coal mining and then at approximately 5-year intervals. As specified by federal law, surveillance is offered to active coal miners, but their participation is voluntary. A large number of PMF cases go undetected by NIOSH through its voluntary program for several reasons.

- First, only a fraction of coal miners participate in the voluntary screening program, largely out of fear that adverse health findings could cause them to lose employment.
- Second, former miners are not eligible to be screened by NIOSH, and therefore many cases will be missed. Moreover, the disease may not appear until after a miner has

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stopped mining. Since a number of mines have closed in recent years, many more former miners are seeking medical examinations to apply for black lung benefits.

Fortunately, former miners are able to obtain diagnostic services from the black lung clinics funded by the Health Resources and Services Administration (HRSA); however, HRSA does not presently report cases of PMF diagnosed through the black lung clinics. Instead, PMF is included with the overall count of cases of coal workers pneumoconiosis.

During the five year interval between August 2011 and July 2016, “a total of 99 unique cases of PMF were detected nationwide” by NIOSH’s surveillance program, according to a recent article in *Morbidity and Mortality Weekly Report (MMWR)*.<sup>1</sup> That article also reported 60 practice-identified cases that were recently discovered in a twenty month interval ending in August 2016 by a radiologist in eastern Kentucky. This cluster of cases was brought to the attention of NIOSH by a single local radiologist, but was not discovered through the national surveillance program offered to active miners. According to the *MMWR* article, “the actual extent of PMF in U.S. coal miners remains unclear.”

Spurred by the cases of severe black lung in Appalachia that were reported by the radiologist in Kentucky, NPR then obtained data from eleven black lung clinics in Virginia, West Virginia, Pennsylvania, and Ohio. NPR’s investigation identified a total of 962 cases of PMF from these clinics so far in this decade. This is ten times greater than the numbers reported by NIOSH through its active miner surveillance program.

For example, at one black lung clinic in Southwest Virginia, approximately 600 miners have been diagnosed with PMF over the past three fiscal years, according to preliminary data. The cases at just this one clinic dwarfs the number of PMF cases reported by NIOSH among active miners nationwide.

There is a third source of data. The Department of Labor’s Office of Workers’ Compensation Programs (OWCP) gathers statistics on PMF cases that have received a Proposed Decision and Order (PDO) under the Black Lung Benefits Act (BLBA). PMF cases are readily identifiable because the BLBA provides claimants with an un rebuttable presumption of entitlement to benefits, if they can demonstrate that they have PMF (or complicated pneumoconiosis) as demonstrated through chest imaging, biopsy, or autopsy. Such determinations by OWCP remain subject to appeal.

Ideally, these three groups of data could be aggregated. It is likely that there will be an overlap between the PMF cases identified by the black lung clinics, the cases identified by NIOSH’s screening program, and cases that have been adjudicated by OWCP. Where there is overlap, case numbers will have to be adjusted accordingly.

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<sup>1</sup> *Resurgence of Progressive Massive Fibrosis in Coal Miners — Eastern Kentucky, 2016*, Blackley, et al, December 16, 2016

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In light of the three agencies' access to data, we are seeking your collective assistance in securing a reasonable estimate of the number of PMF and other severe cases of pneumoconiosis diagnosed in active and former coal miners over the past five years, and to the extent feasible, we also wish to learn how surveillance efforts in this area can be improved so that the full dimensions of black lung in all of its forms can be more readily identified.

We understand that NIOSH is willing to take the lead on aggregating and reporting the information, which in our view would be consistent with their statutory mandate. We hope that this approach is agreeable to both HRSA and OWCP.

Thank you kindly for your consideration of this request. Please contact Richard Miller of the House Committee on Education and the Workforce at (202) 225-3725 or Larry Smar of the Senate Health, Education, Labor, and Pensions Committee at (202) 228-3563 if you have additional questions.

Sincerely,



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**ROBERT C. "BOBBY" SCOTT**  
Ranking Member  
House Committee on Education  
and the Workforce



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**ROBERT P. CASEY, JR.**  
Ranking Member  
Subcommittee on Children and Families  
Senate Committee on Health, Education,  
Labor and Pensions