



# The Association for Frontotemporal Degeneration

Opening the gateway to help and a cure

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March 17, 2017

The Honorable Greg Walden  
Chairman  
Energy and Commerce Committee  
U.S. House of Representatives  
Washington, DC 20515

The Honorable Frank Pallone  
Ranking Member  
Energy and Commerce Committee  
U.S. House of Representatives  
Washington, DC 20515

Dear Chairman Walden, Chairman Brady, Ranking Member Pallone, and Ranking Member Neal:

On behalf of The Association for Frontotemporal Degeneration, a national non-profit organization dedicated to improving the quality of life of people affected by FTD and driving research to a cure, I write to oppose the *Preserving Employee Wellness Programs Act* (H.R. 1313), which recently passed out of the House Education and Workforce Committee. This legislation would wrongfully attempt to tie financial incentives to employee wellness programs at the expense of the crucial privacy and anti-discrimination protections afforded employees with genetically detectable diseases, including frontotemporal degeneration (FTD) and other rare diseases. FTD is a neurological disease that results in progressive damage to the temporal and/or frontal lobes of the brain and is the most common causes of dementia in people under 60. In approximately 15-40% of all FTD cases, a genetic cause (e.g., a gene mutation) can be identified as the likely cause of the disease and in most cases it is an inherited mutation.

Under the Genetic Information Nondiscrimination Act (GINA) and the Americans with Disabilities Act (ADA), employers are prohibited from requiring or even requesting employees to divulge sensitive information related to genetic testing, and are only allowed to offer genetic testing to employees and receive the results of these tests if an employee joins a wellness program *voluntarily*. H.R. 1313 would exempt these protections related to enrollment in voluntary workplace wellness programs, and would impose harsh new penalties on employees who refuse to make this private information public to their employer. The threat of these penalties could be used by employers to force their employees to disclose private genetic information that could later be used against them, costing them their job or their health care coverage.

For patients with genetically detectable diseases or predispositions to such diseases, privacy is crucially important for protecting against workplace discrimination as well as individual independence and dignity. While it aims to expand workplace wellness programs to improve public health outcomes, this legislation would significantly undercut patient privacy protection for employees at high risk for workplace and societal discrimination given the nature and severity of their illnesses or risk of illness. This legislation would also weaken privacy protections for the family members of these employees, whose genetic predisposition to certain diseases may be exposed by the employee's test results.

H.R. 1313 opens the door for unscrupulous employers to misuse the information provided to them through workplace wellness programs and exposes employees to illegal discrimination. Accordingly, we urge you to not advance this legislation through your respective committees and to carefully consider how such legislation will affect the access to care, dignity, and well-being of those individuals and their family members with detectable diseases and conditions.

Sincerely,

A handwritten signature in black ink, appearing to read "Susan L-J Dickinson", with a long horizontal line extending to the right.

Susan L-J Dickinson, MS, CGC  
Executive Director