



January 18, 2022

The Honorable Mark Takano
Chairman
House Committee on Veterans' Affairs
364 Cannon House Office Building
Washington, DC 20515

Dear Chairman Takano:

On behalf of The Michael J. Fox Foundation for Parkinson's Research (MJFF), I write to express my appreciation to you and to the members of the committee for hosting the roundtable on the true cost of our promise to toxic-exposed veterans. Parkinson's disease (PD) is a chronic, progressive neurological disorder affecting over 1 million people, including approximately 110,000 veterans in the United States. All too often, soldiers may experience physiological or psychological stress, head trauma, severe brain injury, or become exposed to dangerous toxins from solvents, burn pits, jet fuel, insecticides, pesticides, or herbicides that are known or suspected triggers of PD.

Estimates indicate that one in six Americans suffers from a neurological condition, and PD is the fastest growing neurological disease in the world and is the second most common condition after Alzheimer's disease. The disease currently costs Americans at least \$58 billion each year and – roughly half of which is through Medicare in caring for people living with PD. By 2037 – just 15 years from now - that cost will balloon to around \$80 billion. Unfortunately, and after 20 years of war, the number of PD patients and the correlating costs for care will increase. The financial impact and rising prevalence, however, can be mitigated through additional federal funding directed at research to treat and cure PD for our nation's veterans and beyond.

Parkinson's gradually worsens over time. Currently, there is no treatment to slow, stop, or reverse the progression of the disease, nor is there a cure. Military service-related exposures, including prisoner of war status, traumatic brain injury, and certain chemical exposures, are associated with increased risk of PD. Additionally, the VA provides a presumption of service-connection for PD to veterans exposed to Agent Orange in Vietnam, veterans exposed to chlorinated solvents in the drinking water at Camp Lejeune, and veterans who have experienced traumatic brain injury.

The treatment of patients diagnosed early with PD can aim to slow down clinical progression, control motor and non-motor symptoms, maintain functioning in daily-life activities, prevent motor complications and minimize risk of side effects. The largest proportion of costs incurred in PD occur in the later stages of the disease. Any strategy that would maintain PD symptoms in the earlier stages of the disease (i.e., fewer and less severe) would likely prove substantially beneficial toward limiting expenditures. From a patient quality-of-life perspective, much the same is true. Considering that the effect of PD on patient quality-of-life is one of the most severe of all chronic diseases, and because the most severe symptoms occur in more advanced disease, care management strategies aimed at early detection and treatment have the potential to improve the experience of living with PD.

The VA's six Parkinson's Disease, Research, Education, and Clinical Centers (PADRECCs) administer care through a National Consortium that offers specialized Parkinson's disease and movement disorder specialty care in over 50 Consortium Centers to veterans who cannot travel to a PADRECC. The mission of the PADRECCs is to support quality of life by providing comprehensive medical and surgical care to veteran patients with PD and other movement disorders, advancing investigation into the cause and cure for PD, and enhancing understanding of the disorder through education and research. For everyone living with PD, including veterans, building the right care team is an important part of navigating life with the disease. This



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should include a movement disorder specialist — a neurologist with specialized training in PD — and, depending on the patient needs, might include allied care professionals such as speech therapists, social workers, mental health counselors, and physical therapists.

Congress is taking a first great step by approving committee report language accompanying the FY22 Military Construction, Veterans Affairs, and Related Agencies appropriations bill directing the VA to significantly increase its investment to maintain and expand the PADRECCs, particularly in unserved or underserved areas, and enhance services provided to military veterans. With a current annual operating budget of \$8 million [*equating to an investment of just \$67 per year (or a mere 18 cents per day) for each veteran living with PD*], this will be an insurmountable endeavor for the six PADRECCs and fifty-three Consortium sites, that receive no supplemental funding, to provide the level of care, education, and research our nation's veterans deserve. With the number of military veterans diagnosed with PD on the rise, we must, and with additional federal funding, can do better.

In addition, and after ten years of level funding at \$16 million, it is time for Congress to increase funding to \$25 million for the Neurotoxin Exposure Treatment Parkinson's Research Program (PRP) administered by Congressionally Directed Medical Research Programs (CDMRP) at the Department of Defense (DOD). Over the past 24 years, the PRP has been a success, but PD is complex, and more research is needed. To date, important research conducted helped to understand head injury biomarkers, the biochemical basis of service member depression, and provided greater understanding of neurodegenerative disease risk as a consequence of military service. As a result, the VA recognizes the link between Parkinson's and some of these stressors – including exposure to certain pesticides and traumatic brain injury. This research is applicable to the general population as well, and several studies originally funded using PRP funds, such as the Parkinson's Associated Risk Study (PARS) — a groundbreaking study that worked to evaluate individuals for early signs of PD — has provided the basis for work on civilians that continues today.

Increasing the investment in research at the VA and DOD on the front end to develop innovative therapies and cures can lower back-end costs. Ninety percent of the Parkinson's population relies on Medicare for health care coverage, and up to one-third of people with PD are dual eligible for Medicaid due to their income or disability status. New treatments would relieve the burden on Medicare, Medicaid, and the Department of Veterans Affairs.

In providing more than \$1.5 billion in PD research to date, The Michael J. Fox Foundation for Parkinson's Research (MJFF) has fundamentally altered the trajectory of progress toward a cure. However, MJFF investments are a complement to, rather than a substitute for, federal programs and federally funded research. Robust and reliable federal research funding is imperative to drive progress. There are many potential Parkinson's breakthroughs on the horizon, which are critically needed by the millions living with this disease and the many more who will be exposed to dangerous toxins known to increase the risk for PD.

Once again, thank you for hosting this important roundtable and for allowing me this opportunity to share important information centered on supporting veterans exposed to harmful toxins. Please contact Dustin Watson at dwatson@michaeljfox.org should you have any questions or require further information.

Sincerely,



Ted Thompson, JD
Senior Vice President, Public Policy