



MISSOURI HOUSE OF REPRESENTATIVES
WITNESS APPEARANCE FORM

BILL NUMBER: HB 822		DATE: 3/21/2023	
COMMITTEE: Children and Families			
TESTIFYING: <input checked="" type="checkbox"/> IN SUPPORT OF <input type="checkbox"/> IN OPPOSITION TO <input type="checkbox"/> FOR INFORMATIONAL PURPOSES			
WITNESS NAME			
INDIVIDUAL:			
WITNESS NAME: JULIA PITCHER		PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:		TITLE:	
ADDRESS:			
CITY:		STATE:	ZIP:
EMAIL: jpitcher@michaeljfox.org	ATTENDANCE: In-Person	SUBMIT DATE: 3/17/2023 12:40 PM	

THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.

March 21, 2023 The Honorable Hannah Kelly, Chairwoman House Children and Families Committee 201 West Capitol Avenue Room 315 Jefferson City, MO 65101 RE: **HB 822 – Missouri Parkinson’s Disease Registry (SUPPORT)** Dear Chairwoman Kelly and members of the committee, The Michael J. Fox Foundation for Parkinson’s Research was founded in 2000 and has been singularly dedicated to finding a cure for Parkinson’s Disease (PD) through an aggressively funded research agenda and to ensuring the development of improved therapies for those living with PD today. We offer our full support for HB 822 which would establish a Parkinson’s Disease Registry in Missouri. A Missouri Parkinson’s Disease registry, along with those already established in California, Utah, Washington, and most recently West Virginia and South Carolina could truly power significant progress toward new treatments, and ultimately a cure for Parkinson’s patients. The registry would provide data on the incidence of the disease and its various patterns in the state, including potential geographic clusters and environmental exposures. Patient registries can provide a real-world view of clinical practice, patient outcomes, safety, and comparative effectiveness. Registry data can also inform policymakers about health care equity disparities and the influences of social determinants of health. Parkinson’s disease is the second most common and fastest growing neurological disease in the world and the number of people with PD is expected to double by 2040. The annual cost of Parkinson’s nationally is at least \$52 billion and that will rise to nearly \$80 billion by 2037. The direct and indirect costs to care for the over 21,000 people living with PD in Missouri is \$1.1 billion per year – finding new treatments and ultimately a cure would save tens of millions of dollars each year. Establishing a state research collection registry will eventually feed into the Center for Disease Control’s National Neurological Conditions Surveillance System which tracks the incidence and prevalence of many neurologic disorders, including Parkinson’s. Researchers around the globe will be able to take state-based data to:

- Help identify high-risk groups, support patient contact studies, and serve as a valuable data resource to prevent and optimally manage Parkinson’s disease. ·
- To determine incidence and prevalence of Parkinson’s disease more accurately by state. ·
- The data will help researchers study patterns of Parkinson’s disease over time. ·
- Help determine if certain regions of the state that use more pesticides have higher a higher incidence of Parkinson’s. Studies have shown a correlation between higher pesticide use and increases in Parkinson’s cases. ·
- Improve our understanding of the link between Parkinson’s and military service since a larger portion of the veteran’s community has Parkinson’s compared to the general population. ·
- Privacy of individual patients is protected rigorously within registries, compliant with the Health Insurance Portability and Accountability Act (HIPAA) and other federal and state privacy laws. When properly designed, a Parkinson’s registry can expand in the future to collect data on other neurological diseases. Given the known, and unknown, neurological impact of COVID-19, a state registry could provide data critical for treatments of future coronaviruses. The registry data

would also provide insight into Parkinson's 'clusters' in the state and would enable greater scientific understanding of exposure of firefighters and other first responders to chemicals, toxins, heavy metals, and other possible environmental factors that may be Parkinson's triggers. On behalf of the foundation and the patients we support, we urge a favorable vote on HB 822. Thank you for your time and consideration, please don't hesitate to contact me at jpitcher@michaeljfox.org or 202-638-4101, ext. 441. Sincerely, Julia L. Pitcher, JDDirector of State Government RelationsThe Michael J. Fox Foundation for Parkinson's Research



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BUSINESS/ORGANIZATION:			
WITNESS NAME: JULIA PITCHER		PHONE NUMBER: 202-638-4101	
BUSINESS/ORGANIZATION NAME: THE MICHAEL J. FOX FOUNDATION		TITLE: DIRECTOR OF STATE GOVERNMENT RELATIONS	
ADDRESS: PO BOX 4777			
CITY: NEW YORK		STATE: NY	ZIP:
EMAIL:	ATTENDANCE:	SUBMIT DATE: 3/21/2023 12:00 AM	
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REGISTERED LOBBYIST:			
WITNESS NAME: LYNNE M. SCHLOSSER		PHONE NUMBER: 913-461-8724	
REPRESENTING: MICHAEL J. FOX FOUNDATION FOR PARKINSON'S RESEARCH		TITLE:	
ADDRESS: 1521 PEPPERWOOD DR.			
CITY: ST. LOUIS		STATE: MO	ZIP: 63146
EMAIL:	ATTENDANCE:	SUBMIT DATE: 3/21/2023 12:00 AM	
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INDIVIDUAL:		
WITNESS NAME: ARNIE C. "HONEST-ABE" DIENOFF-STATE PUBLIC ADVOCATE		PHONE NUMBER:
BUSINESS/ORGANIZATION NAME:		TITLE:
ADDRESS:		
CITY:		STATE: ZIP:
EMAIL: arniedienoff@yahoo.com	ATTENDANCE: Written	SUBMIT DATE: 3/7/2023 11:23 PM
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I am Opposed to this Bill. This is a Private Issue. We do not NEED to Collect Patients and Families Personal Medical Information. We also do NOT NEED yet another "Advisory Council."



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EMAIL: arniedienoff@yahoo.com	ATTENDANCE: Written	SUBMIT DATE: 3/21/2023 11:04 PM	
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I am Opposed to this Bill. This is a Personal Medical Matter and Missouri State Government NEEDS to Say Out of Missouri's Medical Matters. We again do NOT NEED the State to track Missourians.