Brittany Meyer - Michael J Fox Foundation for Parkinson's Research
EPA "Transparency Rule" Testimony as prepared for oral delivery
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My name is Brittany Meyer and I am the Associate Director of Public Policy at the Michael J. Fox Foundation for Parkinson's Research. I am here on behalf of the nearly one – million people with Parkinson's disease in the United States who rely on the Environmental Protection Agency to safeguard their health and inform them about potential hazards in the environment.

Over the past ten years, we've learned a lot about the mechanisms of Parkinson's disease and now know that the condition is caused by both genetic and environmental factors. It is now very clear that when coupled with a genetic risk factor, exposure to several chemicals, most notably solvents and certain pesticides, can trigger the disease. Just eight weeks ago, a study out of Canada suggested low-level exposure to pesticides disrupts cells in a way that mimics the effects of mutations known to cause Parkinson's.[1] More research is needed to fully understand the mechanisms at work and how to prevent them.

Many of the studies used to identify risk factors for Parkinson's disease are investigated via large population based epidemiology studies and will be impacted by EPA's proposal. I am going to highlight one clear example- though along with my health and science colleagues here today, we can provide hundreds of examples of studies that could impacted.

A 2009 study used GPS to estimate participants' well-water contamination exposure from agricultural pesticides. The results showed that consuming water from a private well located in an area with historical pesticide use resulted in an increased risk of Parkinson's disease.[2] Due to the nature of wells — typically serving a relatively limited number of people within a very small radius — the detail needed to perform the study renders proper de-identification impossible. All one needs to know is that a certain person lives near a particular well along with a demographic detail such as their age, gender, race, etc., and privacy is at great risk.

Data from studies like this cannot be de-identified to the degree needed to protect patient's identification while still providing the amount of specificity needed to help a scientist trying to replicate the results. Obtaining consent is not a solution. Some people make the choice to not disclose their Parkinson's diagnosis for a variety of reasons including privacy concerns, fear of prejudice or retaliation at work, and others. It is simply unreasonable to put people in the position of outing their diagnosis or to decline to participate in a study that could someday find a cure for their condition. Additionally, people who are willing to sign away their privacy and those who are not are different in ways we cannot predict or control for in study analysis.

The Michael J. Fox Foundation believes in open, reliable, and replicable science. We fund approximately 90 million dollars in research per year and hold our funded scientists to the highest standards. Our contracts require studies to be peer reviewed and most require data to be

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[1] Stykel, Morgan G. et al. "Nitration Of Microtubules Blocks Axonal Mitochondrial Transport In A Human Pluripotent Stem Cell Model Of Parkinson's Disease". *The FASEB Journal*, 2018, p. fj.201700759RR. FASEB, doi:10.1096/fj.201700759rr. Accessed 17 July 2018.

[2] Gatto, Nicole M. et al. "Well-Water Consumption And Parkinson'S Disease In Rural California". *Environmental Health Perspectives*, vol 117, no. 12, 2009, pp. 1912-1918. *Environmental Health Perspectives*, doi:10.1289/ehp.0900852. Accessed 17 July 2018.

as available as possible while protecting precious health data. We echo the call of our fellow public health groups here today and the nearly seventy public health, science, academic, and medical groups who signed on to a joint statement calling for the rule to be abandoned for the sake of science and for our health. Thank you.