

VIEWPOINT

The Parkinson Pandemic—A Call to Action

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Pandemics are usually equated with infectious diseases such as Zika, influenza, and HIV. However, an imminent noninfectious pandemic, Parkinson disease (PD), requires immediate action.

Neurological disorders are now the leading cause of disability in the world.¹ Among these neurological disorders, the fastest growing is PD, whose growth is surpassing that of Alzheimer disease.¹ From 1990 to 2015, the prevalence of, and thus disability and deaths owing to, PD more than doubled.¹ The Global Burden of Disease Study estimates that 6.2 million individuals currently have PD. Because the incidence of PD increases sharply with age and because the world's population is aging, the number of individuals affected is poised for exponential growth (Figure). Conservatively applying worldwide prevalence data from a 2014 meta-analysis² to projections of the world's future population,³ the number of people with PD will double from 6.9 million in 2015 to 14.2 million in 2040. Applying this same growth rate to the lower estimate by the Global Burden of Disease study (6.2 million in 2015) projects to a staggering 12.9 million affected by 2040.

All these estimates likely understate the true prevalence of PD. The future burden will probably be higher owing to underreporting (record-based studies miss many who have not been diagnosed), declining smoking rates (smoking is associated with a 50% decreased risk of PD), and increasing longevity. Regardless of the exact numbers, if PD were an infectious condition, it would rightly be called a pandemic.⁴

To address this pandemic, the PD community should follow the efforts of the HIV community as detailed in David France's book *How to Survive a Plague*.⁵ In just 15 years, the affected community took what was initially an unknown and rapidly fatal illness and transformed it into one that was highly treatable, allowing millions of individuals around the world to live long, healthy lives. France outlines at least 4 efforts that should be applied to PD.

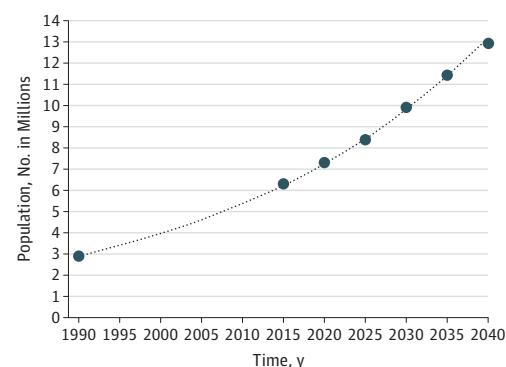
Preventing Transmission or Onset

To combat HIV, the community rapidly changed behavior, including sexual practices, to stem its spread. Beyond genetic factors,⁶ the exact causes of PD have yet to be elucidated. However, increasing evidence suggests both environmental (eg, pesticides) and behavioral influences (eg, lack of exercise and possibly dietary factors) contribute to the disease, and these are addressable.

Increasing Access to Care

Those affected by HIV had very limited access to care. Discrimination was rampant, and some hospitals refused to care for those affected. While less stark, access to care for PD, a highly treatable condition, is also limited. In wealthy nations such as the United States, more than 40% of individuals older than 65 years with

Figure. Estimated and Projected Number of Individuals With Parkinson Disease, 1990-2040



Sources: Global Burden of Disease Study (1990 and 2015) and projections based on published² and public³ sources.

PD do not see a neurologist, and those who do not are more likely to fall, be placed in a skilled nursing facility, and die.⁷ Similarly, an online survey in 35 European countries showed that 40% of respondents had never seen a PD specialist. In less wealthy nations, many are never even diagnosed. In a door-to-door study in Bolivia, none of the individuals found to have PD had ever been diagnosed or received treatment.⁸ Even in countries with specialists, demand for care exceeds supply. China, for example, has more than 2 million individuals with PD and fewer than 100 specialists to care for them.

Increasing Funding for Research

When the AIDS epidemic began, no government funds were devoted to the condition, and many initial efforts were funded and conducted by the community itself. Through intense advocacy, government and industry funding eventually increased, leading to identification of the disease's cause and effective treatments. Today, the National Institutes of Health devotes approximately \$3 billion to HIV research. In contrast, PD, which affects roughly half as many Americans, receives less than \$200 million.⁹

Decreasing the Costs of New Treatments

Early on, the AIDS community realized that new treatments needed to be affordable for those who needed them most. To ensure access, activists took extreme measures when needed, including locking themselves within the headquarters of pharmaceutical companies. Today, because of their efforts, millions around the world have access to life-saving drugs. By contrast, 40% of all countries and 80% of low-income countries do not have access to medications for PD. This includes 50-year-old levodopa, which improves quality of life, reduces mortality, and is relatively safe. Ensuring that new treatments are

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affordable will be increasingly important as new biologics and devices are developed and as the burden of PD shifts from wealthier nations to less wealthy nations.

Such activism is beginning to emerge in the Alzheimer disease community, but for too long, the PD community

has been too quiet on these issues. Building on the AIDS community's motto of "silence equals death," the PD community should make their voices heard. The current and future burden of this debilitating disease depends on their action.

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