Congress of the United States
Washington, DC 20515

June 9, 2004

The Honorable Ralph Regula
Chairman
House Appropriations Subcommittee
on Labor, HHS and Education
2358 Rayburn House Office Building
Washington, D.C. 20515

The Honorable David Obey
Ranking Member
House Appropriations Subcommittee
on Labor, HHS and Education
1016 Longworth House Office Building
Washington, D.C. 20515

Dear Chairman Regula and Ranking Member Obey:

As Co-Chairs of the Congressional Working Group on Parkinson's Disease, we respectfully request your support for increased federal funding for medical research, in general, and particularly for Parkinson's Disease research.

Over the years, Congress has made valuable investments in medical research by supporting the National Institutes of Health (NIH). We ask that you continue your strong commitment to biomedical research funding so that medical advances can be turned into tangible treatment for all debilitating diseases, including Parkinson's disease.

Additionally, we ask that you give every consideration to including the following report language in your FY05 Committee mark:

NATIONAL INSTITUTES OF HEALTH

OFFICE OF THE DIRECTOR
Parkinson's Disease. -- The Committee commends the Director for his strong support and facilitation of collaboration with patient advocacy groups, health non-profits, and international organizations.

The Committee is also aware that the Parkinson's Disease Research Agenda (PDRA) developed by NIH in 2000 included professional judgments funding projections that totaled an additional $1,000,000,000 over five years to achieve a cure. The Committee strongly urges NIH to come as close as possible to fulfilling that Agenda while maintaining the standards of peer review. The Committee strongly urges the NIH to devote additional resources to Parkinson's research, as recommended by the Parkinson's Disease Research Agenda, using all available mechanisms, including RFAs.

Furthermore, the Committee is interested in the development of NIH's Parkinson's disease "matrix." While the matrix was created to establish specific goals set forth by the vision of the PDRA, the Committee strongly encourages the NIH to extend the matrix to include concrete steps toward better treatments and a cure.

The Committee expects the NIH to report to Congress by April 2005, not only on the steps it has taken to fulfill the Parkinson's Disease Research Agenda, but also its progress towards finding a cure for this devastating disease. Additionally, as five years have elapsed since the last NIH

cure for this devastating disease. Additionally, as five years have elapsed since the last NIH conference on Parkinson's disease, the Committee strongly urges the Director to hold another conference, similar to the one held in November of 1999, to examine the path to a cure, working with patient advocacy, scientific, and non-profit communities. The results of the conference should produce a strategic plan setting forth the research funding and programs required to secure the earliest possible development of effective therapies, prevention, and a cure for Parkinson's disease.

OFFICE OF THE DIRECTOR

Roadmap Initiative. --The Committee commends the Director's efforts through the Roadmap Initiative and other efforts to increase collaboration and efficiency within NIH and believes that increased collaboration in the area of Parkinson's disease research, diagnosis, and treatments will greatly advance the search for a cure. Moreover, the Committee urges NIH to explore opportunities in other institutes to advance Parkinson's research, diagnosis, and therapeutics.

NINDS

The Committee urges NINDS, in addition to pursuing all promising therapeutic avenues, such as gene therapy, stem cells, surgical approaches, non-human models, and biomarkers, should continue to identify and study neuroprotectant compounds, such as Coenzyme Q10, creatine, and minocycline.

Furthermore, the Committee encourages NINDS to work with NIBIB to discover a biomarker (particularly a molecular one) for Parkinson's. Investment by NIBIB in clinical trials could greatly enhance the value of these trials, as imaging technology facilitates a better understanding of the physical effects of tested drugs.

Finally, the Committee commends NINDS for committing to set aside funds within its budget to fund the Udall Centers. The Morris K. Udall Parkinson's Disease Research Centers of Excellence support additional research opportunities and discoveries that will lead to improved diagnosis and treatment of patients with Parkinson's disease. The Centers vary in their basic and clinical objectives, but together they foster an environment that enhances research effectiveness in a multidisciplinary setting.

NIEHS

The Committee further urges NIEHS in collaboration with NINDS to gain a greater understanding of the environmental underpinnings of Parkinson's disease. The Committee also strongly urges NIEHS to intensify its efforts in the Collaborative Centers for Parkinson's Disease Research Program—as this initiative facilitates significant collaboration between genetics, clinical medicine, epidemiology, and basic science so that the most promising leads may be investigated more quickly in pursuit of a cure or to reduce the incidence of harmful toxins.

NIA

The Committee encourages NIA to collaborate with NINDS in developing a greater understanding the overlap in benefits that current research could provide to understanding both Alzheimer's and Parkinson's disease. The Committee congratulates the significant investment by NIA in understanding the role of genes, including alpha-synuclein, in the causation and

manifestation of Parkinson's. Work of this nature is critical for better comprehension of the disease process, identification of potential pharmaceutical agents, improved diagnostic ability--especially during the early stages of the disease, and the development of accurate animal models.

NCCAM

In addition, the Committee encourages NCCAM to continue exploration of the neuroprotective qualities of B vitamins and antioxidant phytochemicals in berries via animal models. Research with animals has shown that diets containing berry fruits (such as blueberries) in addition to B vitamins can forestall and perhaps reverse many of the neurological changes associated with age-related neurodegenerative conditions, such as Parkinson's and Alzheimer's disease.

NIMH

The Committee encourages NIMH to increase its research on the role of depression in Parkinson's disease. Particularly, depression may be a very early symptom of Parkinson's, sometimes appearing before other traditional symptoms. NIMH should also continue its ongoing research into the proper treatment of depression and other serious mental disorders that often co-occur with Parkinson's, such as dementia and anxiety.

Sincerely,

LANE EVANS
Member of Congress

CAROLYN MALONEY
Member of Congress

FRED UPTON
Member of Congress

MARK UDALL
Member of Congress