Whom Should I Contact if I Have Questions?

Questions are encouraged. Please contact:

Honglei Chen, MD, PhD
Epidemiology Branch / NIEHS
111 T.W. Alexander Drive
P.O. Box 12233, A3-05
Research Triangle Park, NC 27709

E-mail: chenh2@niehs.nih.gov
NIEHS Web site:
www.niehs.nih.gov

Social & Scientific Systems, Inc.
Study Manager
800-948-7552, Extension 4355

If You Have Questions About the Rights of Research Subjects, Please Contact:

Marian Johnson-Thompson, PhD, Chair
Institutional Review Board for the Protection of Human Subjects
NIEHS
P.O. Box 12233, NH-08
Research Triangle Park, NC 27709
919-541-4265

National Institute of Environmental Health Sciences
and National Cancer Institute
National Institutes of Health
U.S. Department of Health and Human Services
What Is Parkinson’s Disease?
It is a brain disease that affects many elderly Americans. The causes are unknown.

What Is the Purpose of This Study?
The purpose is to learn more about the environment and genes responsible for Parkinson’s disease. This may result in better ways of treating and preventing it.

Who Is Participating in This Study?
- Individuals who told us on the recent NIH-AARP Diet and Health Study survey that they have Parkinson’s disease.
- A sample of individuals who told us they do not have Parkinson’s disease on the recent NIH-AARP Diet and Health Study survey.

Who Is Conducting the Study?
The study is conducted by scientists at the National Institutes of Health (NIH) who have interests and experience in studying Parkinson’s disease.

How Do I Participate?
If you agree to participate, you will be asked to:
1) Sign the enclosed form permitting us to contact your physician for medical records pertaining to your Parkinson’s diagnosis.
2) Complete a one-page form regarding your Parkinson’s diagnosis.
3) Provide a saliva sample for DNA testing.
4) Complete a possible telephone interview later.
The permission form, saliva collection kit, and consent form can be returned to us in the prepaid envelope provided. Return of the completed materials signifies your consent to participate. Please retain this study brochure as your record.

Will I Benefit from This Study?
There are no direct benefits to you. However, you will be contributing to a study providing new insights about causes of Parkinson’s disease and ways to prevent it.

What About My Privacy?
Our staff treats your medical data confidentially, according to strict rules, and the information will be used only for medical statistical purposes. Statistical results may be published in a scientific journal, but individuals’ information and identities will not be released.

What if I Do Not Want to Participate?
Taking part in this research study is voluntary. You may decide not to take part at any time. There is no penalty or loss of benefits to which you may otherwise be entitled.