

Parkinson's Disease and the Family

A NEW GUIDE

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Resources

Families coping with Parkinson's disease never need to feel that they are alone in the world. Organizations and individuals worldwide publish books, host websites, produce newsletters, and answer telephone calls, all about living and coping with Parkinson's disease. We hope that this book has answered many questions. But, as with any other disorder, the vast array of information about Parkinson's disease is constantly being updated with findings and facts that individuals and families might find useful for their own circumstances.

Our advice is to stay informed. Continue to ask questions. Work hard to maintain a high quality of life. Although living with a chronic disease like Parkinson's can be difficult, there are many opportunities for feeling good, and lots of people who can help you discover ways to make life easier or more enjoyable.

Some of the resources in this list are geared toward scientists, physicians, and other professionals. The information may be about the pathophysiology of neuron loss in Parkinson's disease, for example, a challenging topic even for scientists who work in the field. Choose the resources that are the best fit for your level of interest and knowledge.

We believe that the resources we provide here are among the best. The short description that accompanies each resource is meant as an overview of how that agency or website might provide you with some useful insight or tangible help. We find the information that comes from U.S. government organizations and from professional Parkinson's disease foundations especially well researched. Many other resources, such as hospital websites, for example, base their articles and facts on

government reports, so you can save time by going to the original source.

A few words of caution: Avoid advice that sounds unrealistic or questionable. Your physician is the best resource when you have concerns about information received outside his or her office. Your health and well-being are at stake, so move with care through the abundance of information that is available. Much of it is solid, but some is truly spurious and even inaccurate or harmful.

Note that website addresses, phone numbers, addresses, other contact information, and even content are subject to change. We can only guarantee that the information provided here was accurate at the time this book was published. We encourage you to persevere in finding the information that will make you better prepared for whatever is to come.

PROFESSIONAL SOCIETIES

American Academy of Neurology (www.aan.com)

1080 Montreal Ave.

Saint Paul, MN 55116

Tel: (800) 879-1960 or (651) 695-2717

The AAN is a professional society for medical specialists. The stated mission of the AAN is to advance the art and science of neurology, and thereby promote the best possible care for patients with neurological disorders. AAN offers professional development, career enhancement, and practice-improvement opportunities for physicians and other health care providers. The AAN website contains a brief section for the public, with links to other websites dedicated to neurological diseases.

American Neurological Association (www.aneuroa.org)

5841 Cedar Lake Rd., Suite 204

Minneapolis, MN 55416

Tel: (952) 545-6284

The ANA is a professional society of academic neurologists and neuroscientists. The society's mission is to advance the goals of academic

neurology, train and educate neurologists and other physicians in the neurological sciences, and expand the understanding of diseases of the nervous system and their treatment.

U.S. GOVERNMENT AGENCIES AND WEBSITES

ClinicalTrials.gov (www.clinicaltrials.gov)

Many patients and families ask about research in Parkinson's disease, hoping to participate in what is called clinical research or a clinical trial. The website ClinicalTrials.gov lists ongoing research trials, federally and privately funded, and provides information about the purpose of the research, criteria for participation, and contact information. At times, there are forty or more studies listed under the heading of Parkinson's disease. Before joining any trial, speak with your personal physician. Given the sheer number of research trials, it is difficult for one doctor to keep up with all the research being done, and your diligence might reveal a study that could be appropriate for you.

Healthfinder (www.healthfinder.gov)

Healthfinder is an extensive and useful website. It contains health news, information about health care resources, and a library rich with information about health and medicine. Information about Parkinson's disease ranges from general (overviews, descriptions of the disease) to quite specialized (depression and Parkinson's disease, occupational therapy, and more). The healthfinder project is coordinated by the Office of Disease Prevention and Health Promotion (ODPHP).

MEDLINEplus (www.medlineplus.gov)

This website is another authoritative and valuable health-information resource sponsored by the United States government. The site is updated daily in English and Spanish. It is geared toward both health professionals and consumers, and provides facts and findings about more than six hundred conditions. For Parkinson's disease, it reports the latest news and contains information about clinical and laboratory research, disease management, medications, nutrition, treatments, genetics, and legal matters. On February 6, 2003, for example,

the site posted a report that Medicare would cover the cost of deep-brain stimulation for essential tremor and Parkinson's disease. The Parkinson's disease section of MEDLINEplus can be accessed at www.nlm.nih.gov/medlineplus/parkinsonsdisease.html.

**National Center for Complementary and Alternative Medicine
(www.nccam.nih.gov)**

NCCAM Clearinghouse
P.O. Box 7923
Gaithersburg, MD 20898
Tel: (888) 644-6226

NCCAM is part of the National Institutes of Health. The center supports research on complementary and alternative medicine and distributes information and advisories about CAM treatments. One recent clinical trial funded by NCCAM examines the effect of Chinese exercise modalities on physical fitness and motor control. Another tests magnetic brain stimulation in patients with Parkinson's disease and severe depression.

**National Institute of Neurological Disorders and Stroke
(www.ninds.nih.gov)**

NIH Neurological Institute
P.O. Box 5801
Bethesda, MD 20824
Tel: (800) 352-9424 or (301) 496-5751
TTY (for people using adaptive equipment): (301) 468-5981

Like NCCAM, NINDS is part of the National Institutes of Health. NINDS funds research into a broad array of neurological disorders, including Parkinson's disease. Studies in Parkinson's disease are aimed at discovering causes, finding better treatments, preventing the disease, and even finding a cure. A special section of the NINDS website describes the goal for Parkinson's disease research, which is to "ensure that extraordinary opportunities to move toward a cure are adequately supported and that critical obstacles to progress are addressed."

The website of NINDS contains valuable, up-to-the-minute facts and

information about research findings and treatments for Parkinson's disease. It links to the government website ClinicalTrials.gov, which provides information on research studies that are currently recruiting subjects.

PDTrials.org (www.PDTrials.org)

This website was developed as part of a campaign (Advancing Parkinson's Therapy Campaign, or APT) to increase patient participation in clinical trials. The site includes listings of clinical trials exclusively for Parkinson's disease and also regulatory news updates of interest to PD patients. APT is led by the Parkinson's Disease Foundation in collaboration with other PD advocacy groups and in partnership with the National Institutes of Health.

PARKINSON'S DISEASE ORGANIZATIONS

American Parkinson Disease Association

(www.apda@apdaparkinson.org)

1250 Hylan Blvd., Suite 4B

Staten Island, NY 10305-1946

Tel: (800) 223-2732 or (718) 981-8001; Calif.: (800) 908-2732

The national office of the APDA coordinates the operations of sixty-five chapters across the United States and hundreds of support groups. The APDA helps people with Parkinson's disease and their families by providing education, referrals to medical care, and counseling. It is also a funding source for research on the causes and treatment of Parkinson's disease.

Michael J. Fox Foundation for Parkinson's Research

(www.michaeljfox.org)

Grand Central Station

P.O. Box 4777

New York, NY 10163

Tel: (212) 213-3525

The MJFF provides funding for research into causes and cures for Parkinson's disease. A mission of the foundation is to increase the _____
pace of discovery by supporting innovative research. _____

MJFF has partnered with the Parkinson's Disease Foundation, _____

National Parkinson Foundation, Parkinson Alliance, other private funders, and the National Institutes of Health to support a “fast-track” research initiative designed to fund novel research proposals.

Movement Disorder Society (www.movementdisorders.org)

611 East Wells St.
Milwaukee, WI 53202
Tel: (414) 276-2145

The MDS is an international professional society of clinicians and scientists who are interested in Parkinson's disease and other movement disorders. The mission of the MDS is to advance the neurological sciences pertaining to movement disorders by providing educational programs for clinicians, scientists, and the general public and promoting research into causes, prevention, and treatment of the various movement disorders.

National Parkinson Foundation (www.parkinson.org)

1501 N.W. 9th Ave.
Bob Hope Research Center
Miami, FL 33136-1494
mailbox@parkinson.org
Tel: (800) 327-4545 or (305) 243-6666; Fla.: (800) 433-7022

The goal of NPF is—through research support—to find the cause of Parkinson's disease and a cure. Education of patients, caregivers, and the public is also part of the NPF mission through support groups, seminars, and publications.

Parkinson Alliance (www.parkinsonalliance.net)

211 College Rd. East
Princeton, NJ 08540
admin@parkinsonalliance.net
Tel: (800) 579-8440 or (609) 688-0870

The Parkinson Alliance raises money for pilot research projects that allow researchers to qualify for major funding from the National Institute of Neurological Disorders and Stroke of the National Institutes