



Parkinson's
Disease
Foundation

Web
Resources
for
People
with
Parkinson's

SECOND EDITION

Web Resources for People with Parkinson's

The Parkinson's Disease Foundation (PDF) has reviewed the many available resources on the Internet that contain information on Parkinson's to bring you a list of the most useful and relevant websites. If you are searching for information about Parkinson's clinical trials, recent scientific news or the latest issues for advocacy groups...look no further!

In this booklet you will find the ultimate A to Z of websites which contain useful information for people with Parkinson's disease, families and caregivers. Since new sites are being added and existing ones are updated all the time, this booklet is far from exhaustive. If you currently use a website that is particularly helpful or interesting, please email PDF at info@pdf.org or call (800) 457-6676.

National Parkinson's Groups

The websites listed here are not-for-profit organizations that support and serve the Parkinson's community. In addition to providing PD-related news and forthcoming events and activities, many sites offer unique features.

Parkinson's Disease Foundation www.pdf.org

Ph: (800) 457-6676

Founded in 1957, PDF is a leading national presence in Parkinson's disease research, patient education and public advocacy. We are working for the nearly one million people in the US living with Parkinson's disease by funding promising scientific research and supporting people with Parkinson's, their families and caregivers through educational programs and support services. Through our Parkinson's Information Service (PINS), we offer:

- A support service run by trained health professionals and medical staff to answer questions on any aspect of Parkinson's disease through our toll-free helpline, (800) 457-6676, and web service, "Ask the Expert."
- Print and audiovisual educational materials on Parkinson's disease.
- A monthly email blast with the latest scientific and community news.

American Parkinson Disease Association
www.apdaparkinson.org

Ph: (800) 223-2732

Founded in 1961, the mission of the APDA is to "Ease the Burden and Find the Cure" for Parkinson's disease. APDA works to achieve this through research, patient support and education.

- Locate regional APDA Chapters and Information and Referral Centers.

The Michael J. Fox Foundation for Parkinson's Research
www.michaeljfox.org

Ph: (800) 708-7644

The Michael J. Fox Foundation for Parkinson's Research works to find a cure for Parkinson's disease by providing grants to help guarantee that new and innovative research avenues are thoroughly funded and explored.

- See "Community Information" for caregiver and patient resources.

National Parkinson Foundation
www.parkinson.org

Ph: (800) 327-4545

NPF funds scientific research and provides information, support and education for patients, their families and healthcare professionals.

- Access the Discussion Forum for caregivers, a chat room for people with young onset Parkinson's and an open forum on PD.
- Features resources for finding or starting a support group.

The Parkinson Alliance
www.parkinsonalliance.org

Ph: (800) 579-8440

The Parkinson Alliance raises funds through local events, including the Parkinson's Unity Walk in New York City, to support scientific research programs of other PD organizations.

Independent Regional Advocacy Groups

These websites represent independent regional advocacy organizations. Each organization provides a variety of support and other services.

Dallas Area Parkinsonism Society
www.dallasareaparkinson.org

Ph: (972) 620-7600

DAPS was founded in 1978 with the focus of providing and encouraging support groups in the region.

Houston Area Parkinson Society
www.hapsonline.org

Ph: (713) 626-7114

HAPS provides programs and services including free therapy groups (physical, occupational, speech, water and Tai Chi).

Michigan Parkinson Foundation
www.parkinsonsmi.org

Ph: (800) 852-9781

MPF works to provide education, support and research to the PD community.

- *The Messenger* newsletter includes information on support services offered.

Northwest Parkinson's Foundation
www.nwpcf.org

Ph: (877) 980-7500

A Washington State-based nonprofit dedicated to community outreach and awareness within the region and to advocating for increased federal funding for research.

- Offers a free weekly email bulletin with updates on Parkinson's.

Parkinson Association of the Carolinas
www.parkinsonassociation.org

Ph: (704) 248-3722

The Parkinson Association of the Carolinas, based in North Carolina, provides services for people with Parkinson's and their families, friends, physicians, caregivers and the general public.

- Offers referral services for home healthcare and caregiver resources.

Parkinson Association of the Rockies
www.parkinsonrockies.org

Ph: (866) 718-2996

PAR focuses on education, advocacy and support services as well as addressing quality of life issues for people living with Parkinson's in the Colorado area.

The Parkinson's Institute
www.thepi.org

Ph: (800) 655-2273

The Parkinson's Institute seeks to find the cause(s) of and a cure for Parkinson's disease and provides the best available medical care to patients with Parkinson's disease and related movement disorders who live in the California area.

Political Advocacy

Many members of the Parkinson's community work with advocacy groups to garner public support for Parkinson's issues, including quality of life and government funding for research. Below are advocacy groups that work on behalf of people living with Parkinson's.

American Brain Coalition **www.americanbraincoalition.org**

Ph: (763) 557-2913

Founded in 2000, ABC brings together patients with debilitating brain disorders, their families and health professionals.

- Read position papers to learn about ABC's efforts to affect policy change.

Coalition for the Advancement of Medical Research (CAMR) **www.camradvocacy.org**

Ph: (202) 293-2856

An umbrella organization for academic, research, disease and patient organizations that supports investigative freedom in such areas as stem-cell research and somatic cell nuclear transfer.

- Find advice on ways for individuals to contact representatives in Congress.

Grassroots Connection **www.grassrootsconnection.com**

Grassroots Connection provides information and tools to assist people with their individual advocacy efforts.

- Includes tips on how to influence lawmakers to pass legislation.

Parkinson's Action Network (PAN)
www.parkinsonsaction.org

Ph: (800) 850-4726

PAN is the unified advocacy voice of the Parkinson's community.

- Sign up to receive updates on current legislation impacting the PD community.
- Access the grassroots advocacy network, including PAN's state coordinators and members of Congress.

Young Onset

About 15 percent of people with Parkinson's are diagnosed before age 50. These websites are resources for the young onset Parkinson's community.

Movers & Shakers
www.pdadvocates.org

Movers & Shakers is committed to the support, education, outreach and encouragement of the Young Onset Parkinson's Disease (YOPD) community.

- Use the Movers & Shakers chat room to contact other individuals with YOPD.

Young Onset Parkinson's Association
www.yopa.org

The mission of YOPA is to serve all young onset Parkinson's patients by providing them with empathy, information, a connection with the young onset community and a larger voice in advocacy.

- Access mind-stretching games and discussion lists that offer support to those living with young onset Parkinson's.

Clinical Trials

Clinical trials are research studies designed to answer questions about potential new treatments for Parkinson's disease. By participating in a clinical trial, people with Parkinson's can gain access to top care while helping scientists learn more about possible treatments.

PDtrials

www.PDtrials.org

Ph: (800) 801-9484

This website, developed specifically for people with Parkinson's, is part of the *PDtrials* campaign to increase awareness and to help people easily find and understand Parkinson's disease clinical trials. *PDtrials* is led by PDF in collaboration with a consortium of national Parkinson's organizations.

- Search for a specific clinical trial or browse a listing of Parkinson's clinical trials currently enrolling patients.
- Sign up for monthly email bulletins that include new trial listings.

Centerwatch

www.centerwatch.com

Centerwatch is an information service for patients, pharmaceutical companies and research centers that are involved in clinical research.

- Review an extensive list of clinical trials being conducted across the world.
- Subscribe to a free email service which notifies you about new Parkinson's clinical trials in your area.

National Institutes of Health
www.clinicaltrials.gov

A resource site developed by the National Institutes of Health to provide patients, family members and the general public with current information about clinical research studies.

- Find out about current PD clinical trials.
- Access detailed descriptions of the clinical trials process.

Parkinson Pipeline Project
www.pdpipeline.org

A group that provides the patient perspective on new Parkinson's therapies currently in the pharmaceutical pipeline and advocates for the rights of clinical trial participants.

Parkinson Study Group (PSG)
www.parkinson-study-group.org

A nonprofit, cooperative group of Parkinson's disease experts from medical centers in the US and Canada dedicated to improving PD treatments through clinical trials.

- Identify references in scientific and academic journals relating to PD research and clinical trials.
- Find out about PSG clinical trials that are in progress.

Medical Information Sites

Use these websites as a quick reference tool for information on Parkinson's disease. These websites do not serve as a substitute for the advice of a trained medical professional.

Biospace

www.biospace.com

Read reports on biotech and pharmaceutical companies. Can be searched by company and disease indication.

HealingWell.com

www.healingwell.com

An information resource for patients, caregivers and families who are coping with diseases and chronic illnesses.

- Search archives to read transcripts or to view doctor-produced webcasts on PD treatments, research and more.

Medline Plus

www.nlm.nih.gov/medlineplus/parkinsonsdisease.html

Medline Plus offers extensive information from the NIH and other trusted sources on over 600 diseases and conditions. The link above directs browsers to the section on Parkinson's disease.

- Find hospitals and physicians.
- Look up terms in a medical encyclopedia and dictionary.
- Find health information in Spanish.
- Review extensive information on prescription and non-prescription drugs.

Neurology Channel
www.neurologychannel.com

Developed and monitored by physicians, this site provides information for consumers and medical professionals.

- Locate your nearest neurologist through MD Locator™.
- Ask questions of physicians or participate in the Neurology Forum.

Parkinson's Control
www.parkinsonscontrol.com

Developed by medical experts, this site provides a full range of information about Parkinson's disease, current treatment options and the latest research.

- Review video programs with full-text transcripts for an interactive experience.

RxList
www.rxlist.com

Features an index of FDA-approved drugs that enables visitors to look up drug interactions and side-effects.

**US News & World Report
Brain & Behavior Center**
<http://www.usnews.com/usnews/health/brain/parkinsons/park.about.htm>

A Parkinson's-specific site that explains the anatomy of the disease and provides an overview of treatment, symptoms, medications and more. It also includes links to recent news in Parkinson's and a section on managing life with PD.

Science News

Parkinson's is in a stage of exciting scientific discovery. To learn about advances being made and possible new treatments, visit the websites below.

EurekAlert! **www.eurekalert.org**

This online press service created by the American Association for the Advancement of Sciences (AAAS) provides a forum for research institutions, universities, government agencies and corporations to distribute science-related news.

- View the latest science news or access the archive for easily retrievable releases from around the world.

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

NINDS aims to lead the neuroscience community in shaping the future of research and its relationship to brain diseases. NINDS promotes collaboration throughout the scientific community and provides authoritative neuroscience research information for the general public.

- Access the latest neuroscience news and review recent releases.
- Review or print NINDS publications, including *Parkinson's Disease: Challenges, Progress, and Promise*, fact sheets and other educational brochures.
- Access "PubMed" to review abstracts and references from more than 16 million articles, published in more than 4,000 biomedical journals since the 1950s.

ScienceDaily**www.sciencedaily.com**

Described as one of the Internet's leading online magazines and web portals devoted to science, technology and medicine, this free service brings you breaking news about the latest discoveries and research projects.

- Search the archives for “Parkinson’s” to review recent science news from around the world.
- Review a list of other science-related sites aimed at helping web surfers in their online explorations.

WE MOVE**www.wemove.org**

WE MOVE is a nonprofit organization providing a comprehensive resource for movement disorder information and education — primarily for professionals but increasingly for patients and families.

- Review information for patients, professionals and the public about the latest clinical advances, management and treatment options for neurologic and movement disorders.
- Join the e-bulletin service to receive research news and updates.

Listservs

Parkinson's listservs (online discussion forums) have grown as people utilize the Internet to create virtual communities of friendship and support. By joining a listserv, you will be connected to other people with Parkinson's to exchange thoughts, share ideas and learn from the insights and experiences of others.

BrainTalk Communities **brain.hastypastry.net/forums/**

These forums are owned and maintained by the Department of Neurology at Massachusetts General Hospital. Three specific forums are listed for PD.

- Use the search function to review archived topics.

Parkinson Information Exchange Network Online **www.parkinsons-information-exchange-network-online.com**

Also known as Parkinsn list, this email discussion group is one of the largest PD online communities. The Toronto-based group shares information, advice, friendship and news on PD.

- Subscribe by sending an email to: listserv@listserv.utoronto.ca, including "Subscribe PARKINSN" and your first and last name in the message.

Resources and Services

Here you will find a listing of helpful websites for practical information on such topics as Medicare, Social Security and medical alert services.

AARP

www.aarp.org

The AARP is a nonprofit membership organization dedicated to improving the quality of life for people over 50.

- Find news about Medicare and prescription drugs, tips for healthy living, discounts and an email newsletter.
- A search feature helps visitors find an AARP state-based chapter.

Administration on Aging

www.aoa.dhhs.gov

This multi-language website promotes healthy lifestyles by providing information on elder rights, resources, housing, nutrition and services for seniors.

- Review monthly news, tips and resources for caregivers.

Creativity and Parkinson's

www.pdcreativity.org

View works of art by people with Parkinson's and visit a resource section for activities involving creativity.

Eldercare Locator

www.eldercare.gov

Ph: (800) 677-1116

This site connects older adults (60 years and older) and their families with information about programs and services in their area.

The LSVT® (Lee Silverman Voice Treatment) Foundation
www.lsvt.org

The LSVT® Foundation focuses on improving functional communication in individuals with neurological disorders, with a specialty in Parkinson's disease. LSVT® works to enhance vocal loudness by exercising the muscles of the voice box and speech mechanism.

- Provides details on the therapy in both personal sessions and workshop settings.
- Lists locations and dates for workshops.

MedicAlert
www.medicalert.org

MedicAlert is a membership-based organization that works to protect and save lives by relaying identification and vital medical information in an emergency, via a 24-hour emergency response center.

Medicare
www.medicare.gov

This US government website answers questions about Medicare and Medicaid enrolling, billing and plan choices.

- Compare Medicare health services, find a plan and locate participating physicians in your area.

Melvin Weinstein Parkinson's Foundation
www.mwpcf.org

Ph: (757) 313-9729

The Melvin Weinstein Parkinson's Foundation purchases and distributes equipment and supplies essential to maintaining a safe and comfortable environment for PD patients with special needs.

My Parkinson's Info
www.myparkinsonsinfo.com

Find information on Parkinson's topics using the My Parkinson's Info web log.

- Check for updates in the My Parkinson's Info Library.

The Patient Advocate Foundation
www.patientadvocate.org

Ph: (800) 532-5274

The Patient Advocate Foundation is a national nonprofit that serves as a liaison between the patient and their insurer, employer and/or creditors to resolve insurance, job retention and debt crisis matters relative to their diagnosis.

- Download publications on Medicare, insurance, job discrimination and more.
- Access information in Spanish.

PD Index
www.pdindex.org

The PD Index provides a directory of information about Parkinson's that is available on the Internet.

- Includes links for physical and speech therapy and nutrition.

Self-Help Group Sourcebook Online
www.mentalhelp.net/selfhelp/

Includes a “how-to” guide for starting a support group.

Caregivers

At PDF, we strive to support the entire Parkinson's community — not just the person with Parkinson's, but also the friends, families and caregivers who live with the disease. Here is a listing of resources for the essential group that provides care for people living with Parkinson's disease.

CARE **www.pdcaregiver.org**

Caregivers Are Really Essential is a listserv dedicated to caregivers of people with Parkinson's.

- Access archived messages at this site and register to join the list by sending an email to: listserv@listserv.muohio.edu, including "Subscribe CARE" and your full name in the message.

Caregiver Media Group **www.caregiver.com**

Caregiver Media Group provides information, support and guidance for family and professional caregivers.

- Read topic-specific newsletters and feature articles; access archived issues of *Today's Caregiver* magazine and a free subscription to a weekly e-bulletin.

Family Caregiver Alliance **www.caregiver.org**

FCA describes itself as a "one-stop shopping center" for caregivers. It offers a wide array of services and publications based specifically on caregiver needs.

**National Family Caregivers
Association**
www.nfcacares.org

Ph: (800) 896-3650

NFCA is a grassroots organization that was created to educate, support and empower the millions of Americans who care for chronically ill, aged or disabled loved ones of all diagnoses.

- Find information and advice for caregivers, forthcoming workshops, book reviews, reading lists, "how-to" guides, tips and market research reports.

Parkinson's Training for Caregivers
www.parkinsonseducator.com

The Parkinson's Training for Caregivers project is a free online course developed to train caregivers for those with Parkinson's disease in long-term care settings.

- Use this educational tool to learn about aspects of being a caregiver as well as to learn about the disease itself.
- Take advantage of helpful features including video samples and tips for medication management.

Where do I find:

A website where I can ask a question and receive an answer from a medical expert?

www.pdf.org

A neurologist in my area?

www.neurologychannel.com

A PD listserv?

www.parkinsons-information-exchange-network-online.com

Web resources for caregivers?

www.nfcacares.org

Information on current Parkinson's clinical trials?

www.PDtrials.org

Information on advocacy efforts?

www.parkinsonsaction.org

Updates on the latest news in science?

www.ninds.nih.gov

www.sciencedaily.com

Here are tips to help you find accurate and current information on Parkinson's disease.

- Never substitute online information for seeing a doctor.
- Know who maintains and provides the content on a website.
- Check to see when the information was last updated.
- Use common sense and cross-check any material that seems unusual or too good to be true.
- Search engines like www.google.com or www.yahoo.com can help you find information based on key terms.

Parkinson's Disease Foundation

The Parkinson's Disease Foundation (PDF) is a leading national presence in Parkinson's disease research, patient education and public advocacy. We are working for the nearly one million people in the US living with Parkinson's by funding promising scientific research and supporting people with Parkinson's, their families and caregivers through educational programs and support services.

Since our founding in 1957, PDF has funded more than \$50 million worth of scientific research in Parkinson's disease, supporting the work of leading scientists throughout the world.

Main Office

**1359 Broadway, Suite 1509
New York, NY 10018
P: (212) 923-4700
F: (212) 923-4778**

Columbia University Office

**710 West 168th Street
New York, NY 10032**

Midwest Office

**833 West Washington Blvd.
Chicago, IL 60607
P: (312) 733-1893
F: (312) 733-1896**



**Parkinson's
Disease
Foundation**

Hope through Research • Education • Advocacy

**(800) 457-6676
info@pdf.org
www.pdf.org**