

EASTERN IOWA CORRIDOR PARKINSON'S DISEASE RESOURCE GUIDE

A guide to
Parkinson's
resources,
support groups,
and programs in
the Cedar
Rapids/Iowa City
area.





WHAT IS PARKINSON'S DISEASE?

Parkinson's disease (PD) is a neurodegenerative disorder that affects predominantly dopamine-producing ("dopaminergic") neurons in a specific area of the brain called substantia nigra.

Symptoms generally develop slowly over years. The progression of symptoms is often a bit different from one person to another due to the diversity of the disease. People with PD may experience:

Tremor, mainly at rest and described as pill rolling tremor in hands. Other forms of tremor are possible

- Bradykinesia

- Limb rigidity

- Gait and balance problems

The cause remains largely unknown. Although there is no cure, treatment options vary and include medications and surgery. While Parkinson's itself is not fatal, disease complications can be serious. The Centers for Disease Control and Prevention (CDC) rated complications from PD as the 14th cause of death in the United States.

The first step to living well with Parkinson's disease is to understand the disease and the progression:

It is possible to have a good to great quality of life with PD. Working with your doctor and following recommended therapies are essential in successfully treating symptoms by using dopaminergic medications. People with PD need this medication because they have low levels or are missing dopamine in the brain, mainly due to impairment of neurons in the substantia nigra.

It is important to understand that people with PD first start experiencing symptoms later in the course of the disease because a significant amount of the substantia nigra neurons have already been lost or impaired. Lewy bodies (accumulation of abnormal alpha-synuclein) are found in substantia nigra neurons of PD patients.

Scientists are exploring ways to identify biomarkers for PD that can lead to earlier diagnosis and more tailored treatments to slow down the disease process. Currently, all therapies used for PD improve symptoms without slowing or halting the disease progression.

In addition to movement-related ("motor") symptoms, Parkinson's symptoms may be unrelated to movement ("non-motor"). People with PD are often more impacted by their non-motor symptoms than motor symptoms. Examples of non-motor symptoms include: apathy, depression, constipation, sleep behavior disorders, loss of sense of smell and cognitive impairment.

In idiopathic Parkinson's disease, progression tends to be slow and variable. Doctors often use the Hoehn and Yahr scale to gauge the progression of the disease over the years. The scale was originally implemented in 1967 and it included stages zero to five, where zero is no signs of Parkinson's and five is advanced PD. It was later changed to become the modified Hoehn and Yahr scale.

<https://www.parkinson.org/understanding-parkinsons/what-is-parkinsons>

EASTERN IOWA MOVEMENT DISORDER SPECIALISTS

University of Iowa Neurology Clinic - Parkinson's Disease (clinical trials may be available)

2007 Roy J. Carver Pavilion (RCP) - Elevator E, Level 2

www.uihc.org/parkinsons-disease-clinic 319-356-2580

Dr. Ergun Uc

Dr. Annie Killoran

Dr. Kumar Narayanan

Dr. Christopher Groth

Dr. Teri Thomsen

Iowa City VA Health Care System – Movement Disorders Clinic

601 Highway 6 West

Iowa City, IA 52246

www.iowacity.va.gov 319-338-0581 | 800-637-0128

Dr. Ergun Uc

Dr. Annie Killoran

PHYSICAL/OCCUPATIONAL THERAPY PROGRAMS

LSVT “BIG” Program

Intensive one-on-one movement program conducted by a Physical or Occupational Therapist. Improves movement, balance, and gait. Physician referral often required. Most insurance companies cover the cost. Contact clinic for more information.

Unity Point Outpatient Physical Therapy, Cedar Rapids

Michelle Langston, PT, Jenny Jenatscheck PTA,

Karla Simmen, OT, Rosemary Russell COTA 319-369-7331

Mercy Medical Center Outpatient Physical Therapy, Cedar Rapids

Nichole Plagge, PT, DPT 319-398-6020

Cedar Valley Physical Therapy, Cedar Rapids

Todd Neighbor, PT, DPT 319-294-6694

Kepros Physical Therapy & Performance, Cedar Rapids

Lauren Saehler, PT, DPT 319-200-6102

UIHC Physical Therapy, Iowa City

Stephanie Evans, PT, DPT or Amy Yotty, PT, DPT, or Rachel Rose, OT 319-356-2663

VA Medical Center, Iowa City

Brooke Lantz, PTA or Rachel Murphy, PT 319-338-0581

Progressive Rehabilitation Associates, Iowa City

Kayla Uhlenhake, PT, DPT 319-354-2429

On With Life, Coralville

Paula Duve, PT 319-259-6224

Ability Physical Therapy, Marion

Rachel Richers, DPT 319-373-7311

SPEECH THERAPY PROGRAMS

Lee Silverman Voice Training

Vocal training conducted by Speech Language Pathologists. Voice training is important for those with PD to maintain or regain a strong voice, plus maintain or improve swallowing. Swallowing difficulties are common in the later stages of PD. Physician referral often required. Most insurance companies cover cost.

Unity Point – St Luke’s, Cedar Rapids
Renee Perlwitz, SLP 319-369-7331

Mercy Medical Center Council St, Cedar Rapids
Kelly Martin, SLP 319-398-6881

Wendell Johnson Speech and Hearing Clinic, Iowa City
Ann Fennell, SLP 319-335-8736

SPEAK OUT!®

SPEAK OUT!® followed by The LOUD Crowd® is a two-part speech therapy program for individuals with Parkinson's developed by Parkinson Voice Project. SPEAK OUT!® consists of intensive individual speech therapy sessions and the goals are to strengthen the muscles for speech/swallowing and to teach individuals to speak with intent. Upon graduating SPEAK OUT!®, individuals transition to the maintenance program, The LOUD Crowd®

Progressive Rehabilitation Associates, LLC
Megan Batzer, M.A., CCC-SLP 319-688-7630
In-patient: Mercy Iowa City Out-patient clinics: Mercy Medical Plaza and Tipton

Wendell Johnson Speech and Hearing Clinic
Ann Fennell M.S., CCC-SLP 319-335-8736

Unity Point – St Luke’s, Cedar Rapids
Renee Perlwitz, M.S.,CCC-SLP 319-369-7331

**Please visit www.crmetroparkinsons.com for current program offerings. Some programs may be suspended or held online via Zoom due to COVID-19.*

LINN COUNTY EXERCISE/ WELLNESS CLASSES

All exercise/wellness classes are held at the Eastern Iowa Parkinson's Wellness & Resource Center 260 33rd Ave SW, Suite G Cedar Rapids
Contact Kris Cameron 319-361-7673 kriscameron@crmetroparkinsons.com for class information, or visit www.crmetroparkinsons.com for a current schedule.

Moving With Parkinson's Exercise
M/W/F 11:15am-12:00pm

Parkin-Singers
Thursdays 2:15pm-3:00pm

Chair Yoga
Thurs 12:00-1:00pm

Cedar Rapids Support Group Third Thursday of each month (no regular meeting in Dec)
4:00pm I-380 Biz Hub studio, 260 33rd Ave SW Cedar Rapids

JOHNSON COUNTY EXERCISE/ WELLNESS CLASSES

Moving With Parkinson's Exercise
Wednesdays/Sundays 12:45pm-1:45pm \$5/class or \$50 punch card
The Center 28 S Linn St Iowa City
Contact Kris Cameron 319-361-7673 or kriscameron@crmetroparkinsons.com

Rock Steady Boxing
Mondays and Wednesdays at 3:30PM and at 12:00PM on Saturdays
ICOR Boxing 1127 Shirken Drive Iowa City
Contact Clif Johnson & Emily Klinefelter at 319-244-8282 or
iowacity@rsbaffiliate.com
Website <http://iowacity.rsbaffiliate.com/>

Iowa City Support Group
Third Tuesday of each month at 6:00pm Grand Living Bridgewater, Coralville
Contact Wanda Crombie w.crombie@mchsi.com 319-330-3131

STATE ASSOCIATIONS (Iowa)

AMERICAN PARKINSON'S DISEASE ASSOCIATION – Iowa Chapter
(Sign up for quarterly magazine and notification of Annual Iowa Parkinson's Conference)
<https://www.apdaparkinson.org/community/iowa/> or 515-241-6379

PARKINSON'S FOUNDATION-CENTER OF EXCELLENCE AT THE UNIVERSITY OF IOWA
<https://uihc.org/news/ui-named-center-excellence-parkinsons-care>

NATIONAL ASSOCIATIONS (online and hotline)

Parkinson's Foundation www.parkinson.org Helpline 1.800.4PD.INFO (1-800-473-4636) for answers to all your questions. Staffed by nurses, social workers and therapists, the Helpline is here to support you in any possible way. Offers online webinars so you can learn at home about the latest research, developments, and wellness. (request free "Aware In Care Kit" containing tools and information to share with hospital staff during a planned or emergency hospital visit)
If you are newly diagnosed, visit www.parkinson.org/Living-with-Parkinsons/Managing-Parkinsons/Advice-for-the-Newly-Diagnosed

Michael J Fox Foundation www.michaeljfox.org 1-800-708-7644
Research and advocacy focused. Get involved in research and trials in your area or join Fox Insight, an online clinical study. Data is being collected for the study right here at the University of Iowa.
Offers online webinars so you can learn at home about the latest research, developments, and wellness.

American Parkinson's Disease Association www.apdaparkinsons.org 1-800-223-2732
The American Parkinson Disease Association (APDA) is the largest grassroots network dedicated to fighting Parkinson's disease (PD) and works to assist the more than 1 million Americans with PD live life to the fullest.
Offers online webinars so you can learn at home about the latest research, developments, and wellness.

Davis Phinney Foundation for Parkinson's www.davisphinneyfoundation.org
866-358-0285
Wellness focused (request free "Every Victory Counts" manual and/or "Parkinson's Exercise Essentials" DVD)

CAREGIVING SUPPORT

*All the above associations offer caregiver information and support.

Family Caregivers Center of Mercy 901 8th Ave. SE Cedar Rapids (319) 221-8866
The Family Caregivers Center of Mercy is Eastern Iowa's only comprehensive resource serving family caregivers caring for adults. Services are available for caregivers regardless of their hospital or physician affiliation.

Unity Point Caregivers Support Group 1026 A Ave NE Cedar Rapids
Mondays 4:00-5:00pm St. Luke's Hospital 6th Floor Lounge

National Alliance for Caregiving www.caregiving.org
The Caregiver Space www.thecaregiverspace.org
Well Spouse Association www.wellspouse.org

RECOMMENDED PUBLICATIONS

- *Brain & Life Magazine* (American Academy of Neurology) www.brainandlife.org
- *10 Breakthrough Therapies for Parkinson's Disease* (book) Michael S. Okun M.D.
- *300 Tips for Making Life with Parkinson's Disease Easier* (book) Shelley Peterman Schwarz
- *A Parkinson's Primer: An Indispensable Guide to Parkinson's Disease for Patients and Their Families* (book) John Vine
- *Parkinson's Treatment: 10 Secrets to a Happier Life* (book) Michael S. Okun M.D.
- *A Life Shaken* Joel Havemann
- *Brain Storms: The Race to Unlock the Mysteries of Parkinson's Disease* Jon Palfreman
- *Both Sides Now: A Journey from Researcher to Patient* (book) Alice Lazzarini, PhD
- *A Funny Thing Happened on the Way to the Future: Twists and Turns and Lessons Learned* (book) Michael J. Fox
- *A Soft Voice in a Noisy World* Karl Robb
- *The New Parkinson's Disease Treatment Book: Partnering with Your Doctor to Get the Most from Your Medications, 2nd Edition* (book) Dr. J. Eric Ahlskog
- *Parkinson's Diva: A Woman's Guide to Parkinson's Disease* (book) Maria De Leon MD

*For books, please check your local bookstore or www.amazon.com



Parkinson's Foundation PATIENT SAFETY KIT



The Parkinson's Foundation launched the Aware in Care campaign in 2011 to help people with Parkinson's disease (PD) get the best care possible during a hospital stay. Research has found that three out of four people with Parkinson's do not receive medications on time when staying in the hospital, and that when this occurs two out of three will experience unnecessary complications. With more frequent hospital visits and a high sensitivity to the timing and dosing of PD medications, people with Parkinson's face great risks in the hospital.

At the Parkinson's Foundation, it is our mission to help people with Parkinson's disease live better lives, and that includes staying safe while in the hospital. We want to help people affected by PD to be "Aware in Care," which means they:

- Understand the risks associated with hospital stays.
- Have tools to play an active role in their care.
- Are prepared for a hospital visit, whether planned or unplanned.
- Have a plan to get the best possible care in the hospital.

People with Parkinson's disease living in the United States can order their free kit at www.parkinson.org/Living-with-Parkinsons/Resources-and-Support/Patient-Safety-Kit Or by calling the Parkinson's Foundation Helpline 1-800-4PD-INFO (473-4636)



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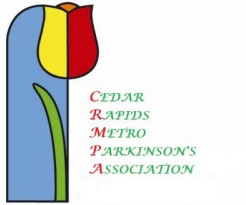


Sheet Metal Workers
International Association
Local 263



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PO Box 931 Cedar Rapids 52406 www.crmetroparkinsons.com

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If you are a provider of Parkinson's healthcare or services and would like to be listed in the guide, please email kriscaeron@crmetroparkinsons.com