AMERICAN PARKINSON DISEASE ASSOCIATION IOWA CHAPTER NEWSLETTER

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UNDERSTANDING THE GENETIC CONTRIBUTIONS TO PD

By Dr. Erin Foster, PhD, OTD, OTR/L

Understanding the genetic contributions to Parkinson disease (PD) is a high priority priority. It will allow scientists to develop better predictions of disease risk as well as targeted and effective treatments. Although PD can affect anyone, regardless of their race, ethnicity or ancestry, studies of the genetics of PD have primarily included people of European descent and/or those who identify as White. This lack of diversity has resulted in an incomplete picture of the risk, biology, and treatment of PD across populations and has limited the generalizability and impact of research findings. In particular, Black and African American people are largely underrepresented in PD research studies. In addition to limiting our understanding of the biological basis and clinical course of PD, this underrepresentation has contributed to considerable health inequities and disparities among Black and African American people with PD, including later diagnosis, lower access to specialized care, and worse health outcomes.



UNDERSTANDING THE GENETIC CONTRIBUTIONS TO PD (cont.)

To address this problem, the Global Parkinson's Genetics Program (GP2), supported by the Aligning Science Across Parkinson's initiative and implemented by The Michael J. Fox Foundation for Parkinson's Research, launched the Black and African American Connections to Parkinson's Disease (BLAAC PD) study. BLAAC PD is a multi-site study in the United States that aims to create a cohort of 2,000 people of Black and/ or African American ancestry (1,000 with PD and 1,000 without) to help researchers better understand the genetics of PD. It has enrolled over 730 participants to-date. Critically, thanks in part to data contributed by the BLAAC PD study, a new genetic risk factor for PD has been discovered! By expanding PD research to involve underrepresented populations, we are already broadening our knowledge of the genetics of PD. Such information will benefit ALL people with PD by increasing our understanding of the risk and

contributors to PD, bringing us closer to the creation of personalized and targeted treatments.

Washington University School of Medicine in St. Louis, UChicago Duchossois Center for Advanced Medicine, and Rush University Medical Center are sites for the BLAAC PD study and are actively recruiting adults with or without PD. Also, you do not need to identify as Black or African American to help! If you are interested in contributing to our effort improve health equity and reduce health disparities among people with PD by increasing diversity and representation in PD research, clinical care, and community services,

please contact: **Dr. Erin Foster**at erfoster@wustl.edu!

St. Louis area:

NIL-BLAACPD@email.wustl.edu
Or Kandace Davis at phone number



Visit your Local Fareway Store and Support Parkinson's Programs in Iowa!

From April 14th-19th, Fareway Grocery Stores statewide will be holding a round-up at the register to benefit the APDA lowa Parkinson's Programs. Every penny helps support essential resources and programs for those living with Parkinson's in Iowa. We encourage you to visit your local Fareway and show your support for this incredible campaign. A big thank you to Fareway for making a difference in our PD community!

AMERICAN PARKINSON DISEASE ASSOCIATION IOWA CHAPTER

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LIVE A GREAT STORY!

An interview with Carole Deyoe by Ann Scherer

I had the joy of interviewing Carole Deyo. She will be a speaker at the Iowa Parkinson Conference in June. Her topic is *Laughing at Tigers* and once she begins, I can assure that you will be thoroughly entertained and enlightened.

Carole, a two time survivor of cancer, knows first hand how to make one's life livable while facing major stressors, and it is our good fortune that she will share the art of finding humor and using humor to be healthier.

Carole admits she didn't always feel positive. She dealt with and faced doubt and depression. Her gift to herself, and now us, is that she was always able to find humor in life and to laugh. This she found, helped her face major life blows and this attitude led her to become a standup comic where she learned to love the reaction of making others laugh. However, she found more purpose in becoming a motivational speaker and reaching out to others with her message.

As a writer, my mind went in its writing direction and I thought of the song, The Eye of the Tiger, by Survivor. I wanted to define the tiger. I couldn't. That's Carole's message. But the lyrics refer to being determined and resilient in the face of adversity. I'm thinking laughter will play a big part.



I asked her to give me something to hold onto until the conference and she said, "Live a great story."

2025 APDA lowa PARKINSON'S CONFERENCE

Empowering you

Friday, June 6th



IOWA CHAPTER

Strength in optimism. Hope in progress.

Keynote Speakers

- Laughing at Tigers- Carole Deyoe RPh A little laughter is good medicine and a lot of laughter can be a contagious cure!
- Exercise to Reduce PD Symptoms Daniel Corcos PhD
- · The Gut-Brain Connection in PD -Richard Manfready MD
- The Latest PD Treatments Lynn Struck MD

Breakout Sessions

- FAQ, Ask the Doc: Keith Kohout MD and Alex Eischeid MD
- Fueling the Fight: Nutrition Strategies to Support Parkinson's Symptoms and Enhance Well-Being Jessica Schroeder RDN LD
- · Improving Outcomes through Rehabilitation Therapy -Jillian Jones DPD
- Finding Local Area Education and Resources Leah Brooke MS, RDN, LD and Crystal Doig
- Exercise Options Boxing and Dance Brandon Brockshus and Brenda Tubelo Pereira de Mattos
- · Care Partners Support Lynhon Stout MSW and Valerie Stickel Diehl RN MS
- · DBS, Is it right for me? -Jeremy Greenlee MD
- Parkinson's Disease and the Road Ahead: Addressing Challenges and Solutions to Driving Kelsee Hove OTD and Michelle Flora, COTA, CBIS
- · Cognitive Fitness: More than Crossword Puzzles Cassie Serrata MS-CCC-SLP
- Exercise Options Yoga and Tai Chi Brandon Brockshus and Brenda Tubelo Pereira de Mattos



CAROL DEVOE



DANIEL CORCOS, PHD



RICHARD MANFREADY, MD



LYNN STRUCK, MD

More Information

June 6th from 8:00 - 4:00

Lutheran Church of Hope

925 Jordan Creek Parkway

West Des Moines



apdaia@apdaparkinson.org



515-207-6296



Tickets

\$15 Individual \$25 Individual & Care Partner

Registration Required

Scan for more information!

EXERCISE IS KEY

by Anne Scherer

We are told from the moment we are diagnosed with Parkinson's disease that exercise as a part of our regimen is vital. An expert on that very concept is Dr. Daniel Corcos, PhD. He is dedicated to the study of exercise as a treatment for Parkinson's disease at Northwestern Medicine, and luckily for us, will be one of the keynote speakers at the Iowa Parkinson's Disease Conference on June 6.

Dr. Corcos explains that he studied how healthy people move their limbs to discern the difference in muscle performance of people who have Parkinson's disease. This became the basis of his continuing studies of movement and exercise. With compelling evidence, it is an imperative to relate the importance of exercise as a main line therapy for the disease.

While all manner of treatment plays an important role in managing Parkinson's, to fight the good fight we must exercise the muscles of the body that allows us to keep moving and doing it safely.

Dr. Corcos will outline four key components of exercise: aerobic, resistance, flexibility, and neuromotor (posture, gait, balance, and agility.) These four components, when done properly and often, may delay the disease progression.

Dr. Corcos left me with these words which should become our mantra: "You must do more to maximize a better life experience living with Parkinson's."





Study Title: Study in Parkinson Disease of Exercise Phase 3 Clinical Trial: SPARX3

We are seeking volunteers to participate in a clinical research trial to learn more about the effects of aerobic exercise on people with Parkinson's disease.

You may be eligible to participate if you:

- Have been diagnosed with Parkinson's disease within the last 3 years and are not yet taking medication for your PD symptoms
- You do not plan to start medication for PD within the next 6 months
- Are willing ot take part in a regular treadmill exercise program 4x/week for 18 months and participate in study visits periodically for 24 months
- Are 40-80 years old
- Are not already participating in a structured exercise program

Principal Investigator: Dr. Elizabeth Stegemoller - Iowa State University, Kinesiology Department If interested, please contact Caelia Marshall, 515-294-5476 or cmarshal@iastate.edu

Participants will be recruited under study number STUDY20110328

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Support Group Schedule



Strength in optimism. Hope in progress.

Ackley - Ackley Civic Center 2nd Wednesday 2:00 - 4:00 pm

Anamosa - Jones Regional Medical Center 1st Monday 3:00 pm

Bettendorf - Palmer Hills Retirement Center 3rd Saturday 10:00 am - 12:00 pm

Burlington - Great River Medical Center 3rd Thursday 2:00 pm

Carroll - St. Anthony's Regional Hospital Thursday 11:00 am

Centerville - MercyOne
Last Thursday 10:30 am March - October

Creston - Salem Lutheran Church3rd Monday 2:00 - 3:30 pm Starts February 2025

Des Moines

*NEW LOCATION - Wesley on Grand 1st Wednesday 2:00 pm

Dubuque - Unity Point Finley Hospital 3rd Saturday 10:00 - 11:00 am

Fairfield - Jefferson County Health Center 1st Tuesday 4:00 pm

*NEW Forest City - Forest City YMCA 1st Friday 10:00 am

Fort Dodge - Friendship Haven Schmoker Building 1st Wednesday 11:30 am - 12:30 pm

*NEW Indianola - The Village 3rd Thursday10:00 am

lowa City - Grand Living at Bridgewater 3rd Tuesday 6:00 - 7:00 pm

Leon - Decatur County Hospital 3rd Thursday 10:00 am

Marshalltown - YMCA 2nd Tuesday 10:30 am

Mason City - MROM-RSB MC 3rd Tuesday 2:30 - 3:30 pm

*New Northwood - Viking Activity Center
1st Tuesday 1:00 pm

Osceola - Clarke County Hospital 2nd Wednesday 1:00 - 2:00 pm

*New Ottumwa - Ottumwa YMCA 1st Tuesday 1:00 pm

Sioux City Siouxland Center for Active Generation 4th Monday 1:00 pm

Sioux Center - Crown Pointe Estates 2nd Thursday 2:00 pm

Spirit Lake - Bedell Family YMCA 1st Tuesday 10:45 am

Storm Lake - St. Mark Lutheran Church 2nd Tuesday 1:30 pm

*NEW Urbandale - Senior Helpers 3rd Wednesday 2:00 pm

Waukee - Independence Village3rd Friday 1:30 pm

Waverly - Waverly Health Center 3rd Thursday 1:30-3:00 pm

Webster City - Van Diest Medical Center 3rd Tuesday 11:00 am - 12:00 pm

West Des Moines
*NEW Edgewater - 3rd Monday 1:00 pm

Grand Living Tower Place - 3rd Saturday 10:00 am

*New Location - Rock Valley Physical Therapy - 2nd Tuesday 12:30-1:30 pm

Exercise Class Schedule



Strength in optimism. Hope in progress.

Ankeny - Edencrest Siena Hills

Wed 10:00 am - Movement Training Level 1

Creston - Salem Lutheran Church

Mon 1:30 pm - Movement Training Level 2

Des Moines - Northside Senior Center

Wed 10:00 am - Movement Training Level 1

Des Moines - Des Moines Ballroom

Mon 6:30 pm - PD Moves Dance

Grimes - Climb Iowa

Every other Tuesday 9:00 am - Rock Climbing Level 3

*Begins April 22 and runs through August 31

Indianola - Indianola Senior Center

Thurs 12:00 pm - Movement Training Level 2

Iowa City - Iowa City Senior Center

Wed 10:00 am - Movement Training Level 2

Pleasant Hill - Edencrest at Pleasant Hill

Sat 9:45 am - Movement Training Level 1

Waukee - Independence Village

Mon 11:00 am - Movement Training Level 2 Fri 11:00 am - Movement Training Level 3

Upcoming Events PD Activities

Connecting Through Art

1st Tuesday, 2:00 pm, March - June | Art making activity around the Metro 3rd Tuesday, 2:00 pm, March - June at the Des Moines Art Center | Art discussion experience

PD Moves, Ballroom Dance class - Starts Monday, March 3, 6:30 pm at Des Moines Ballroom

Education

PD Essentials - A one hour class that is an introduction to Parkinson's, what it is, treatment options, ongoing resources and support.

2nd Tuesday, at Senior Helpers Conference Room, 2951 86th St., Urbandale | Register online

In Person PRESS - April 8

Parkinson's Education Program - Wednesday, May 15, 5:30 pm | Dr. Struck presents: Managing PD

APDA Iowa Parkinson's Conference - June 6, 8:00 am - 4:00 pm

LIVING YOUR PERSONAL BEST

by Valerie Stickel-Diehl, RN, MS, MSCN



Please check with your healthcare provider before you make changes in your fluid intake.

Hydration vs. Dehydration

When Parkinson's Disease changes your life, you can take steps to prevent complications and worsening of symptoms. Let's explore some strategies to help you become a well-hydrated person. Prevention is better than intervention!

Dehydration can cause an URGENT need for medical intervention. It is a common reason elderly people go to the hospital.

Symptoms of Dehydration

- Confusion, sudden memory loss, headaches, dizzy, foggy
- Falling, balance issues, low blood pressure
- Fever due to urinary tract infection or aspiration pneumonia
- Constipation, and dark yellow urine, increase in need to urinate
- Excessive sleepiness, difficulty waking up
- Change in response to medications
- · Sticky mouth, thick saliva, dry eyes

Causes of Dehydration

- Lack of thirst, fluid intake is less than needed to support organs
- Fever from infection, sweating and breathing
- Medications, over the counter and prescriptions
- Alcohol, Caffeine

Why is hydration so vital? Below is a list of some of the places hydration helps in our bodies.

- Brain and Spinal Cord/Central Nervous System/ Circulatory system
 - Brain Volume (fluid) Spinal Fluid (fluid) Cell Nutrients (fluid) - Eyes/Vision - Temperature Control, (cooling and heating) - Fluid Movement from Feet and Legs

• GI and Kidneys

 Digestion - Colon Health and Function - Kidney function and Bladder Health-Flush out Toxins - Transport and Metabolize Medications and Nutrients



• Sinus-Ears-Mouth-Throat

- Taste, Chewing, Swallowing, Saliva - Mucous membranes moist - Dental health, gums and teeth

Skin

Largest Organ - Protects you from bacteria, injury and cancer
 Scalp - Itching

Here is a plan that can help you drink more water: Week One:

Morning: Drink **16 ounces** (2 cups) of water to start your day of rehydration. You can expect to eliminate this in about 45 - 60 minutes. It may take two visits to the bathroom to completely empty your bladder. Remember your entire body needs to be replenished.

Noon: Repeat

Evening: Repeat. The timing of this should be before 6:00 pm, which will allow for more water if desired before bedtime. Now, your intake is at **48 ounces**.

For an added bonus, when you take a pill, drink **8 ounces** (1 cup). Never dump water out of your glass – drink it.

Week Two:

Add 16 ounces (2 cups) in the middle of the afternoon. Now you have successfully added 64 ounces of water to your daily routine.

Things to consider:

Bladder capacity is **16 ounces**. Wear some protective clothing until your bladder adjusts to holding 16 ounces. You are in training.

If you are not active, set a timer to go to the bathroom 45/60 minutes after drinking every 16 ounces. Movement leads to internal movement - the signal to urinate can be delayed if not moving, causing you to feel out of control.

Carbidopa/Levodopa timing is also a good way to get hydrated. Drink when your medication is working to assist with reaction time, to get a better signal and to get up and go.

You will feel better in time and you will start to feel MORE thirsty – reminding us to drink more water.

I hope this helps you live your personal best!

NUTRITION STRATEGIES TO SUPPORT PARKINSON'S SYMPTOMS

Parkinson's disease (PD) affects movement, coordination, and quality of life. While there is no cure, nutrition plays a key role in managing symptoms, improving well-being, and supporting brain health. A well-balanced diet can help optimize medication effectiveness, maintain energy levels, and reduce complications. Here are key nutrition strategies for individuals with Parkinson's:

1. Eat a Balanced Diet

Focus on nutrient-dense foods:

- Fruits & Vegetables Rich in antioxidants, vitamins, and minerals to combat oxidative stress.
- Whole Grains Provide fiber for digestive health and sustained energy.
- Lean Proteins Poultry, fish, tofu, beans, and lentils maintain muscle strength.
- **Healthy Fats** Omega-3s in salmon, flaxseeds, and walnuts support brain function.

2. Manage Protein Timing for Medication

Levodopa, a primary PD medication, can be affected by protein intake. To improve absorption:

- Space protein intake throughout the day.
- Take levodopa 30-60 minutes before meals.

3. Stay Hydrated & Maintain Electrolytes

Dehydration can worsen symptoms like dizziness and constipation. Stay hydrated by:

- Drinking 6-8 glasses of water daily.
- Eating hydrating foods like cucumbers and watermelon.
- Consuming electrolyte-rich foods like bananas and leafy greens.

4. Support Gut Health

Digestive issues like constipation are common in PD. Improve gut health by:

- Eating 25-30g of fiber daily from fruits, vegetables, and whole grains.
- Consuming probiotic foods like yogurt and kefir.
- Staying active to promote digestion.

5. Reduce Inflammation and Support Brain Health

Chronic inflammation is linked to neurodegeneration. Anti-inflammatory foods include:

- Turmeric & Ginger May reduce inflammation and support brain function.
- Green Tea Contains polyphenols with neuroprotective effects.
- Berries Provide antioxidants that support cognitive health.

6. Maintain Bone & Muscle Strength

People with PD are at increased risk of falls and fractures. Key nutrients include:



- Calcium Found in dairy, fortified plant milks, and leafy greens.
- Vitamin D Obtained from sunlight, fatty fish, and fortified foods.
- Magnesium Supports muscle relaxation and nerve function.

7. Manage Weight & Energy

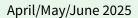
Weight changes are common in PD. Maintain a healthy weight by:



- Eating small, frequent meals if appetite is low.
- Choosing nutrient-dense foods like avocados and nut butters.
- Engaging in regular physical activity to preserve muscle mass.

Final Thoughts

A well-planned diet can improve quality of life for those with Parkinson's. Working with a healthcare professional or dietitian can help create a personalized nutrition plan. Small dietary changes can significantly impact symptom management and overall health.



MY STORY: Life without Dopamine

by Sally Bohmer



Dopamine is like dusting—no one notices it unless you don't do it.

Dopamine has lots of important functions you never think about unless it's not there doing them. I took dopamine for granted until my body didn't make enough anymore. That's

a basic description of Parkinson's Disease (PD)—a deficiency of dopamine. The part of my brain where dopamine is made, the substantia nigra, is damaged.

If you google "dopamine function," you get a list of all the things dopamine does. The main functions have to do with movement, memory, and motivation or mood. Dopamine enables you to focus, learn, remember, problem solve. It allows you to experience pleasure, happiness, and enjoyment of life. This is why it is called the "feel good" hormone. If you read such a list, you would probably say, "I want some of that."

It might be tempting—whether Parkinson's or not—to try taking this "feel good" hormone, but it's not that simple. Like all drugs there are unintended effects like uncontrolled movement (dystonia) and lowered blood pressure. It is believed that too much dopamine damages neurons, so managing the dosage is complicated too. It's a trade-off or balancing act between the benefits and side effects.

After 15 years of PD, I'm trudging along fairly well with regard to movement and memory, but I am not dealing as well as previously with the mood and motivation aspects. I thought it was funny to tell people that apathy is one symptom of PD (which it is) and then say that there are things one can do about it but I didn't care. But I do care. In light of the fact that

these are likely the best days of what I have left of my life I don't want to waste it. My life is trickling away being spent on nothing useful because I don't have the motivation to do anything.

Dopamine is a part of the reward system that keeps us doing things that are good for us. When we do something good we get a burst of dopamine, which we want to repeat. Without this I have to do things because I ought to, which is not as strong a motivator as "want to." I do things like exercise, brushing my teeth, even playing sports or socializing because I know they are important not because they bring me joy. My fun isn't as much fun anymore.

I miss the pleasure of the reward that a burst of dopamine, the "feel good" hormone, gives me when I do something good. This means my highs aren't as high as they used to be but on the other hand because of apathy my lows aren't as low either. There are some good things about not caring. I don't get as upset about not being able to do things well. I don't care as much about what people think. However, given a choice I would trade that for a few more joys.

In light of all this, there are times when it would be easy for me to have a pity party. This is why it is good to know that my conditions such as reduced emotions, social withdrawal, lack of motivation, tiredness are symptoms of PD and not weaknesses in my character. I do know God is with me, for he has promised never to leave me or forsake me. There are still many good days. Best of all I have great, helpful people who care for me and about me. Life is still good, but I do miss my dopamine.







Wednesday, May 14

Dr. Struck Presents: Managing Parkinson's

AN APDA PARKINSON'S EDUCATION PROGRAM

Gain a better understanding of a PD diagnosis

Learn about treatment options and strategies



Get tips for managing symptoms and your well-being

Grand Living at Tower Place 540 S 51st St., West Des Moines

> 5:30 - 6:30 PM In-person



SPACE IS LIMINTED, **REGISTRATION REQUIRED**





to register

Elevate Church 1421 Geneva Street Sioux City, IA



MARTY WALSH **Exercise for PD**



DAN RUBEN Voice/Speech



STEGEMOLLER Singing with PD



ELIZABETH ALLISON OWINGS Managing PD



JESSICA SCHROEDER **Nutrition Strategies**



KAY ARVIDSON Living with PD





Strength in optimism. Hope in progress.

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