



Welcome to the 2023 Healthy Parkinson's Communities™ Leadership Conference

September 14, 2023

Agenda: “We ARE Innovators”



As you arrive this morning...

Start an inventory scan of your body, energy, and mood.

- ***Notice*** where you feel pain and discomfort; where you feel better than you did yesterday.
- ***Write*** notes of what you notice.



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Moment of Victory



Celebratory Welcome
with Davis Phinney, Founder, Davis Phinney Foundation



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Keynote Presentation



Metaphor, Medicine & Parkijazz!

*with Wayne A. Gilbert, Practitioner of Metaphor Medicine
and Parkiejazz*





As you listen to these poems...

Write some thoughts down as you listen to these poems:

- What do you notice?
- What feeling or feelings arise during the poem?
- What does the poem make you think of or remind you of?

<brain to wayne>

elec\trick spaced(ust)
blink/blink dopa-flaked
neuro bubb star|bust
linked un) linked un(con
nect(ed flashchem
is(try) zzt zzt zzt
un)leash/re(lease[d]
5-6-7-8-sssssss s[t[e[p[
shuffdubb shuffdubb
ahlight







Questions to consider

Write down your thoughts:

- What do you notice?
- What feelings arise? How do you *FEEL*?
- What does it make you think of or remind you of?





Movement Break



Movement Break

with Doug Pickard, Ambassador, Parksville, BC, Canada



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Deep Dive into Support Groups



*Karen Frank,
Ambassador,
St. Louis, MO*



*Carolyn Utesch,
Ambassador,
Bloomington, IN*



*Doug Pickard,
Ambassador, Parksville,
BC, Canada*



*Stan Livingston,
Ambassador,
Madison, WI*

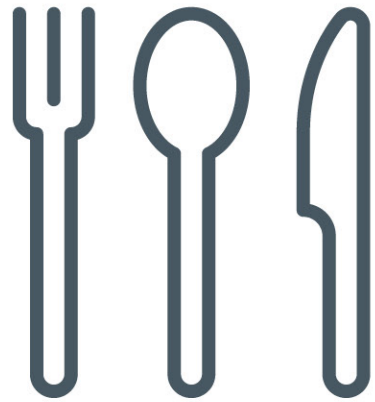


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Lunch Break

*Programming will begin
again at 12:30 pm CDT*



Movement Break



Movement Break

*with Mayra Torres, Hispanic Ambassador Leader,
Phoenix, AZ*



SkillShare Breakouts



“Using Mindset for Consistent Outcomes” - *Memorial Hall*



“How to Create and Foster a Unique Needs Based Support Group” - *Johnson Great Room*



“How Come Grandpa Doesn’t Smile Anymore?” - *Ski U Mah*

Using Mental and Physical Mindset For Consistent Outcomes

Brett Miller, PT

Founder and Owner, 110 Fitness





Foundation Is Critical

- Finding the needle in the haystack!
 - Credentialed and credible programming executed by professionals.
 - Performance is based on research evidence.
 - Variety of programming based on the research.



Finding The Other Needle In The Haystack!

- Community community community! Within the wellness center.
 - Accountability
 - Shared objectives and goals
 - Common understanding of life with Parkinson's (connection)
 - Value of a relationship (COVID, SLPDQ)

Discipline Equals Freedom

- Hydration (3.4L/day)
 - Pill metabolism
 - Pressures
- Clean eating
 - Mediterranean diet
- REST
- High intensity exercise programming daily (HIIT)
- Meditation
- Journaling



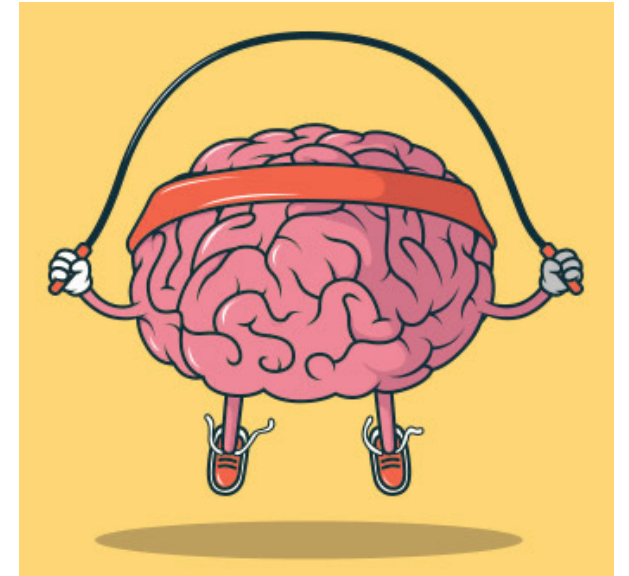
We All Want CONSISTENT FUNCTION

- We function better in our community.
- We recognize there is less risk of injury being disciplined with structure.



Keeping The Mindset

- Volunteer if available and being of service to others that may not be well.
 - Let's talk about dopamine response!
- Set small goals that are achievable and measurable.
- Mindful memory – remember how you felt after your last workout.
 - Was it awesome or do I need to put in more discipline?
- Using meditation and self actualization as a means of fitness achievement.



Role Playing

- How would you encourage?
- How would you motivate to keep mental focus?
 - As a coach
 - As a fellow fighter



Thank you!



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Rockland, MA 02370

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Coffee/Snack/Stretch Break

*Programming will begin again at
1:45 pm CDT*



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SkillShare Breakouts



“Overcoming Challenges to Create Victories; Lessons learned in facilitating a Parkinson’s support group” - *Memorial Hall*



“Speaking to the World About Parkinson’s - Sharing your life with others” - *Johnson Great Room*



“How to Set Up Your Davis Phinney Foundation Table” - *Ski U Mah*

Overcoming Challenges to Create Victories;

*Lessons learned in facilitating a
Parkinson's Support Group*

With Doug Pickard and Stanley Livingston

10 Reasons To Join A Support Group



10 Benefits of Joining a Support Group

1. You'll discover you're not alone
2. It is a safe place to express your honest feelings about your disease
3. You can pick up practical tips about how to deal with PD
4. You may realize you are stronger than you think. It may help you to stay motivated to manage your PD and stick to treatment plans
5. You may discover more inner peace



10 Benefits of Joining a Support Group

6. You may become more self-aware
7. You can help and uplift others.
8. You can help build a sense of community
9. Knowledge is power, sharing makes this condition a little less scary. You may gain a sense of empowerment, control or hope
10. Parkinson's can be isolating. Socializing is important

Top 10 Characteristics of an Effective Parkinson's Support Group Leader



Top 10 Characteristics of an Effective Leader

1. Model supportive talk. Be empathetic as group members contribute their ideas and feelings
2. Encourage group ownership of the group. “What do we want our group to be?”
3. Prepare talking points on a subject. Every Victory Counts and Davis Phinney webinars are excellent sources to find information to bring to the discussions.
4. Balance the positives and negatives of having Parkinson’s. Avoid complaining exclusively. What are some strategies that can help with the challenges of PD? Are there any positive aspects of having the disease?
5. It’s OK to say you don’t have the answer. Can the group solve the problem?



Top 10 Characteristics of an Effective Leader

6. Be a good listener.
7. Go with the flow. If the discussion departs from the announced topic, see where the discussion leads. What is the group interested in? Circle back to the announced topic if necessary
8. Model contribution to the discussion. What have been your personal experiences with the topic?
9. Solicit discussion topics from the group?
10. Summarize the various contributions that the individuals have made.

Top 10 Pitfalls to Avoid when Facilitating a Parkinson's Support Group



10 Pitfalls to Avoid

1. Avoid creating a “Leader and Audience” scenario
2. Avoid playing videos that are too long or too technical
3. Make sure your speaker isn’t trying to sell a product or service, and ensure that the information they put forth is legitimate and relative
4. Anticipate that things might not go as you planned, and be open to “pivoting” and changing directions
5. Anticipate loss. Group members will come and go, and it’s wise to have a plan in place to honour members who pass away in a respectful and positive manner



10 Pitfalls to Avoid

6. Delegate! Don't try and do it all yourself
7. Encourage participation, but don't put anyone on the spot
8. Anticipate that there will be a wide variety of responses to the information you put forth, and don't be disappointed if the group isn't as excited about it as you are, or even challenge its validity
9. Be organized, and be flexible
10. Don't pretend you are the expert in all things related to PD

Group Discussion!

Challenges that may Arise



Common Challenges

1. A member of the group shares that he /she is no longer able to do a cherished activity because of Parkinson's
2. An individual with Parkinson's that has been attending group meetings dies
3. An individual monopolizes the group discussion
4. An individual is very quiet and does not contribute to the discussion
5. An individual tends to complain or “gripe” excessively
6. ...Any other ideas?

Thank You!



Reflection, Networking, *and* Closing



Welcome to the 2023 Healthy Parkinson's Communities™ Leadership Conference

September 15, 2023

**Agenda: “Creativity Lives Within
All of Us”**



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Deep Dive into Fundraising with Team DPF



*Michelle Lane,
Ambassador,
New Orleans, LA*



*Kimerly Coshow,
Ambassador,
Blue Ridge, GA*



*Susan Sapir-Fields,
Director, Louisiana
Walks for Parkinson's*



*Lauren Kehn,
Team DPF
Manager*



*Rebecca Reifel,
Events and
Development
Manager*







TOUR DE VICTORY



LOUISIANA
WALKS
FOR PARKINSON'S

LOUISIANA WALKS





COPPER TRIANGLE







TEAM DPF




**TEAM
DPF**
every victory counts.

RIDE THE ROCKIES



Movement Break



Movement Break

*with Barb Matheny, CAC Leader & Ambassador,
Findley, OH*



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Deep Dive into How to Engage Your Community with New DPF Programs



*Kayla Ferguson,
Community Grants
Manager*



*Devon Fulford, Director
of Education*



Davis Phinney Foundation

Pedaling for Parkinson's & PD Self

Background and Timeline

Pedaling for Parkinson's was founded by leading Parkinson's researcher Dr. Jay Alberts of the Cleveland Clinic to advance our understanding of how cycling and physical activity impacts the motor symptoms associated with Parkinson's.

Since the first Pedaling for Parkinson's classes began in just a few YMCA's in 2013, the program has taken hold and become a significant provider of accessible exercise, community connection, and wellness for people living with Parkinson's. At its height, the program has had at least 175 active sites across the country and served 2,000+ participants.

COVID 19 has had a profound impact in Pedaling for Parkinson's; it's estimated that 80-90% of host sites ceased operations during the 2020 shut down and many have failed to restart.



Research

2009 - BRAIN TRAINING: EFFECTS OF AEROBIC EXERCISE IN PARKINSON'S DISEASE

This study examined the effects of exercise on cognitive and motor functioning in a group of newly diagnosed individuals with Parkinson's.

The overall goal of this study was to assess whether exercise had potential to slow Parkinson's progression in individuals who had not yet been treated with anti-Parkinson's medications. Participants in this project exercised on a stationary exercise bicycle in their home that was linked to study coordinators in the lab.

Results suggested that aerobic exercise has a strong potential to slow the progression of Parkinson's symptoms in individuals not yet treated with anti-Parkinson's medications.



Research

2018 - COMMUNITY-BASED CYCLING CLASS FOR SLOWING DISEASE PROGRESSION

Dr. Anson Rosenfeldt and Dr. Jay Alberts are examining if Pedaling For Parkinson's (an existing, low-cost program hosted by YMCAs) can slow Parkinson's progression. This team is following 50 participants and tracking their motor symptoms, non-motor symptoms, number of classes attended, and quality of life over a 12-month period.

This project also aims to identify which individuals respond the most (more slowing of Parkinson's progression) to this type of exercise. This project builds off Dr. Albert's earlier work funded by the Davis Phinney Foundation and represents a translation of clinical research to everyday life.

Pedaling for Parkinson's Project Plan Overview

June 1 –End of year - “Quiet” phase: Begin sharing with close stakeholders and potential partners. Execute projects in upcoming slide

Early 2024 – Announcement!

Project 1: Agreements, Waivers, Processes

Project 2: Software

Overview: Determine all the software we need to:

- o Manage agreements
- o House and share PFP branding package
- o House and share PFP training
- o For PFP online --> collect and store participant waivers and emergency contacts

Project 3: Website and Communications

Project 4: Training and Onboarding

Project 5: Funding and Partnerships

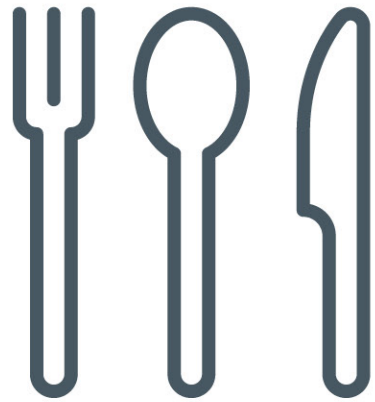
Project 6: PFP Online (to take place Q1/Q2 of 2024)

PD Self: What Is It?

- International training for people diagnosed with Parkinson's in last three years
- Eight session online program presented biweekly
- For people with Parkinson's and care partners
- Facilitated by teams in partner (PwP, care partner, health professional)

PD Self: Next Steps

- Learn more about becoming a PD Self trainer!
- Informational webinar October 12, 12-1 pm MDT
- Share the message with your community
- Reach out: blog@dpf.org



Lunch Break

*Programming will begin
again at 12:30 pm CDT*



SkillShare Breakouts



“Death Café” - *Memorial Hall*



“Employment Law and Parkinson’s - Wisdom, law, and practicality in the world of Parkinson’s” - *Johnson Great Room*



“Care Partner Workshop” - *Ski U Mah*



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Death Cafe

With Amy Carlson



Coffee/Snack/Stretch Break

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1:30 pm CDT*



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SkillShare Breakouts



“Growing a Local Parkinson’s Organization” - *Memorial Hall*



“How to Share Your Parkinson’s Management Techniques” -
Johnson Great Room



“Free Time” - *Ski U Mah*



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Growing a Local Parkinson's Organization

With Rick Buck

Zanesville, Ohio

- Population: Less than 25,000
- Famous for: The Y Bridge





President/Founder

The Zane's Trace Commemoration:

1. Three-day festival
2. Family-friendly entertainment
3. Features a parade, educational history exhibits, crafters and exhibits, demonstrations, arts & crafts, entertainment and of course plenty of food!



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Local group: (That I was unaware of)

- Zanesville Parkinson's Group/All Shook Up
- Been around since 2011
- Did not have any outreach to others
- Presently 30 active participants

I became President of group March 8, 2023 without any planning on my own.

So... now I am president and I get started right away looking into the things that were in desperate need of change.

1. I completely built a new website
2. I designed the logo below
3. I filed paperwork that had not been filed for the past few years
4. I wrote and received a Grant for Parkinson's Awareness, outreach and education



- We have two exercise classes on Tuesday mornings to accommodate all the members.
- We have pool exercise at the YMCA on Thursdays
- We have a support group which meets monthly
- We have literature that I have put together to reach out to those with Parkinson's or know someone that has Parkinson's

A few of the Parkinson's members getting ready for the parade




Set up with information at the Zane's Trace Commemoration



- **Coaching other members does not always come easy.**
- **There can be many challenges and sometimes even failures.**
- **However, I believe in trying to find positivity and purpose in everything that I set out to do.**

One of the rack cards I put together

(Front)



Do you or someone you know have Parkinson's?

We are the Zanesville Parkinson's Group and we are here to help improve the quality of life for individuals with movement disorders.

Through constant support, education, and community outreach we strive to foster a culture of optimism and improved physical & emotional health for patients and families.

We help give people with Parkinson's disease hope by improving their quality of life through a non-contact boxing based fitness curriculum.

Significant research studies and anecdotal evidence highlight the critical importance of exercise for people with Parkinson's.

Regular physical exercise can improve mobility and coordination, boost your mood, reduce stiffness, and minimize soreness and fatigue.

And each year, more studies prove that exercise may slow the progression of Parkinson's itself.

(Back)

TUESDAYS EVENTS

Every Tuesday

First group 9:30 am-10:30 am
Second group 10:30 am-11:30 am

3297 Maple Avenue
Zanesville, Oh
(In Country Fair Shopping Center)

Rock Steady Boxing
Balance Control
Gait Training
Core Strengthening
Chair Volleyball for FUN!
\$5 per person
All exercises are led by licensed therapists.

THURSDAY'S EVENTS

Every Thursday, from 10 am-11 am

YMCA
1425 Newark Road
Zanesville, Oh
(Behind Zane State College)

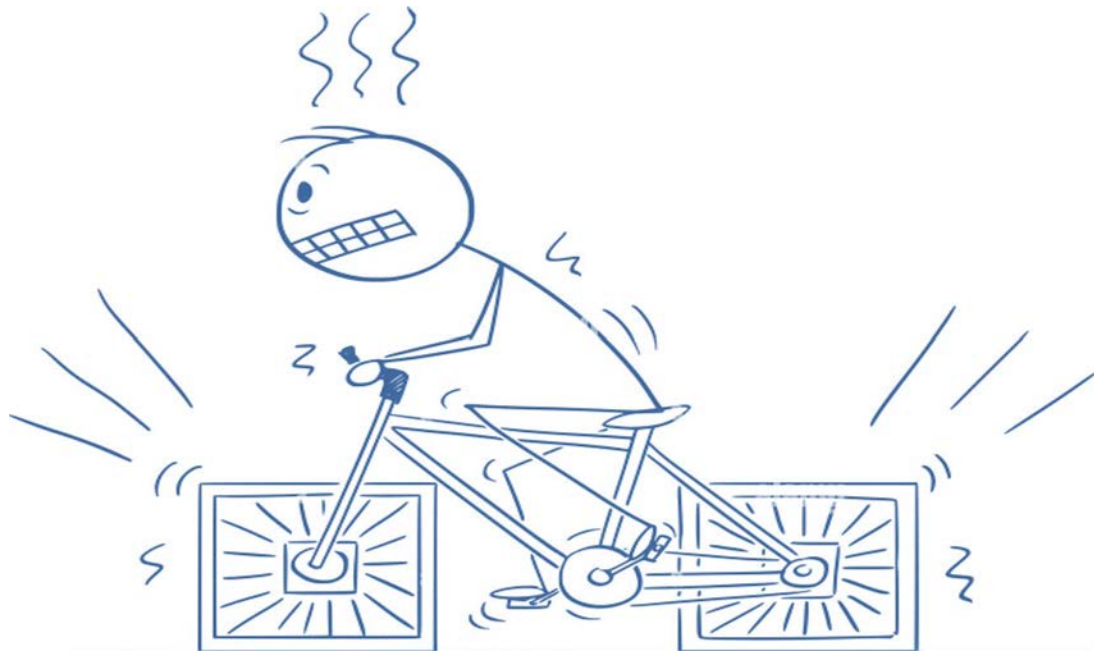
Aquatic Exercise
No Swimming Involved
Free! Free! Free!
All exercises are led by licensed therapists.

We welcome you to come and join us.

For more information:

Website: zpg-allshookup.com
Follow us on Facebook.
Email: zanesvilleparkinsons@gmail.com

The Zanesville Parkinson's Group
is a 501 (c)(3) nonprofit organization.



Sometimes we can feel like we are getting no where. However, with positivity and purpose things will happen.

As we move forward, I believe that we will continue to help improve the quality of life for individuals with Parkinsons. Through constant support, education, and community outreach we will strive to foster a culture of optimism and improved physical & emotional health for patients and families.



Moment of Victory



Thank You & Closing
*with Polly Dawkins, Executive Director, Davis Phinney
Foundation*

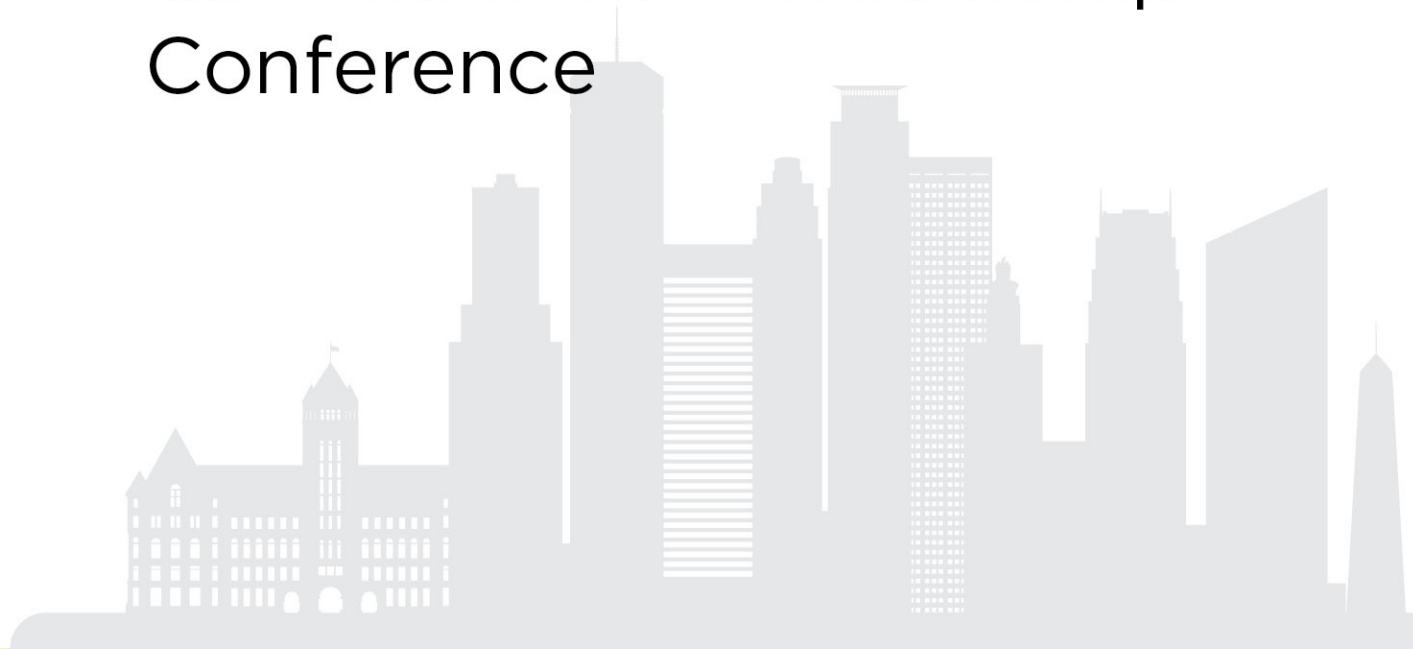


Reflection, Networking, *and* Closing



THANK YOU FOR COMING!

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