PARKINSON'S SUPPORT GROUP OF ASHEVILLE

"You are not alone"

http://www.parkinsonsavl.org
ParkinsonsAVL@gmail.com
(828) 579-7897

NEWSLETTER
SEPT./OCT. 2024

PSG-AVL group member Les Vann with his service dog, Dale

OUR ANIMAL COMPANIONS

Research has shown the benefits of pet ownership for most people – and Parkinson's patients are no exception. These include:

- *Health*: Both mental and physical well-being are improved with pet interaction
- *Socialization*: Getting outside, meeting other people
- Relief from stress and anxiety
- *Unconditional love*: Who can resist a tail excitedly wagging to welcome you home?
- *Entertainment*: Dogs chasing squirrels, a purring cat in your lap...

See p. 8 for full story

THIS MONTH

UPCOMING MEETINGS

*1st Tuesday of the month
10:00am
Groce United Methodist Church

Tuesday, September 3

Topic: Drug research and development, with Jocelyn Kakavas of the MJFF

Tuesday, October 1

Topic: Movement disorder specialist Dr. James Patton

See p. 3 for details

NEW NEWSLETTER & HAPPENINGS FORMAT!!

starting this month

See p. 2 for details

BEERS AND CHEERS

(3rd Thursday of each month)

Thursday, September 19
&
Thursday, October 17
5:30pm
Highland Brewing
12 Old Charlotte Hwy

LETTER FROM THE EDITOR

NEW NEWSLETTER FORMAT!

Since March 2023, I have enjoyed the privilege of helping to produce the Parkinson's Support Group of Asheville newsletter. It has been an evolving and challenging process and I've learned a lot more than I'd ever anticipated. Sean Simonds and I worked together to compile an organized newsletter with topics that would engage, educate, and interest our members.

As Sean's practice has grown and I've become more comfortable with the editing process, I've gradually assumed the editor position with assistance from my daughter Kate. It has consumed much of my time and energy, and as those with Parkinson's know, time and energy are golden!

This past issue, July/Aug., was a double issue due to no meetings those two months. As I had been considering publishing fewer newsletters, and appreciated having more than a couple of weeks "off," we've decided to shift to producing a **bimonthly newsletter** (with Board approval), and alternating with a **bimonthly update email** called "**WNC PD Happenings.**"

The full newsletter will still include group news and updates, spotlights on national news relating to Parkinson's, and features such as the recurring Our Journeys with Parkinson's and other topical content. The Happenings email will contain up-to-date info on the coming months' general meetings, small group meetings (including Chat & Chew and PwP small groups), exercise opportunities, and any other scheduled events. The current newsletter covers September and October, while **the first of the Happenings emails should come out toward the beginning of October.**

> We've decided to shift to producing a bimonthly newsletter alternating with a bimonthly update email called "WNC PD Happenings."

I want to thank all those who have contributed their Journeys with Parkinson's, as I know they are very personal. I'm also grateful to those who have allowed me to interview them or sent photos to complement articles. A special thanks to Sean who kept the newsletter ball rolling and continues to be an important asset to our PD community.

We hope you will all enjoy and benefit from these changes. Any and all suggestions and contributions are more than welcome.

Jane Rigot, Newsletter Editor

Notice of 2025 Annual Dues

The annual dues for the Parkinson's Support Group of Asheville are due **September 3.**

Dues are critical for financing the day-to-day operation of our group, and your prompt response will be appreciated.

The dues for 2025 remain **$40 for two people** (person with Parkinson's plus one spouse, partner, caregiver, or any other person who will be participating in group activities with you). Dues for a **single person are $25**.

Dues can be paid by **credit card**, by **check**, or **in cash** at the monthly meeting or at Beers and Cheers.

Credit card payments can also be made online here:
Dues for two people: https://square.link/u/WF5bdCjW
Dues for one person: https://square.link/u/rfMIi3v2

Checks also can be mailed to:
Parkinson's Support Group of Asheville
825 C Merrimon Ave., PMB #327
Asheville, NC 28804

September Program to Focus on Research and Drug Development of the Michael J. Fox Foundation

Jocelyn Kakavas, MJFF ambassador

Jocelyn Kakavas will speak at the Asheville Parkinson's Support Group meeting on September 3. Kakavas, a **Michael J. Fox Foundation (MJFF) ambassador for the Southeast** and a member of the foundation's advancement team, will give a brief overview of MJFF's role in the Parkinson's community, accompanied by a **research update** covering **biomarker breakthroughs**, current **drugs up for regulatory approval**, and drugs in the pipeline.

Kakavas will highlight the MJFF's **Parkinson's Progression Markers Initiative (PPMI)**. Launched in 2010, PPMI aims to validate biomarkers of Parkinson's onset and progression. It expanded in 2020 to include more participants and sites. The initiative **follows people with and without PD over time to understand disease progression, leading to better diagnosis, treatment, and prevention**.

The study has grown to over fifty international clinical sites and aims to increase participant numbers significantly. The foundation shares its extensive dataset and bio-sample library to support other studies and accelerate breakthroughs.

Kakavas will talk about recent drug research advances, including drugs to improve mitochondrial function and targets surrounding alpha-synuclein aggregation, which could slow or stop Parkinson's progression.

She will also share **how members of the support group can become involved in MJFF's drug and therapy trials** across the nation.

The Fox Foundation was founded in 2000 by actor Michael J. Fox. It is dedicated to finding a cure for Parkinson's disease through an aggressive research agenda and ensuring the development of improved therapies for those living with the condition.

The meeting will include **time for attendees to ask questions** of clarity or information not covered in the presentation.

October's meeting will be **Tuesday Oct. 1st.**
The featured speaker will be
movement disorder specialist **Dr. James Patton.**
Full details will be included in the first "Happenings" email to be sent out in September.

SAVE THE DATE!

Join the Fox Foundation in October for a free educational event in Charlotte

The Fox Foundation's highly regarded **Parkinson's IQ + You** educational event and expo comes to Charlotte on **October 19** at Le Méridien hotel.

The in-person program will feature interactive sessions about living with Parkinson's, making the most of doctor visits, building a comprehensive care team, and the latest research and the value of research participation.

Check-in begins at 9 a.m. The program runs from **10:00 a.m. until 2:15 p.m.**, and includes breakfast, a boxed lunch, and light refreshments throughout the day.

More information and registration can be found at https://www.michaeljfox.org/parkinsons-iq-you . MJFF encourages **early registration** to ensure a spot.

TUESDAY
SEPT. 3

The Asheville Parkinson's Support Group meets at Groce United Methodist Church at 954 Tunnel Road in east Asheville on the first Tuesday of each month at 10:00 a.m. for refreshments, socializing, and announcements.

The program begins at approximately 10:30 a.m. and runs for 30 minutes, with additional time for questions.

Fun for all at our 2024 Annual Picnic

by Jane Rigot

Our Parkinson's Support Group of Asheville picnic began with what might become an annual bear visit. However, this young bear seemed to be content sniffing around the lawn of the Governor's Western Residence, rather than at the scent of food that was starting to waft from under the gazebo.

Approximately 92 people attended, enjoyed meeting new members and old acquaintances, and chowed down on the excellent buffet and desserts.

The picnic crowd enjoying the afternoon repast in the gazebo at the Governor's Western Residence

An attendee suggested that we could include a recipe of the month in our newsletter – this might be a good place to start, as we seem to have some pretty good chefs among us! Many thanks to all the volunteers, cooks, and organizers who helped us to have a fun afternoon.

We were serenaded by local musicians Vollie McKenzie and Friends, with many lively bluegrass songs. The cornhole and other yard games, although not quite the caliber of the concurrent Olympic games, provided some exercise to work off the desserts.

Our afternoon's entertainment, Vollie McKenzie and Friends

Outreach & Media Chair Jody Watts presents a plaque to outgoing Chairman of the Board Ed Horton.

This year's bear attendee

Outreach Chair Jody Watts made a presentation to Ed Horton on behalf of the group, thanking him for his many years of devotion to the organization, and commenting on the varied hats he has worn during those years. As many of you may know, Ed recently stepped down as Chairman of the Board of Directors and from other leadership roles, but continues to be active in our group.

The plaque, which recognized Ed for his "extraordinary commitment and effort to revive and grow this vital community resource," was presented in memory of Jane Bingham, who was instrumental in the founding of the Parkinson's Support Group of Asheville.

Keep moving, Ed!

My YOPD journey

by Laura Anderson

I remember standing in the kitchen holding a full glass of water in my left hand with my arm stretched out. My arm was trembling slightly, which was something new I had not felt before. While bathing my dog and washing my hair, I also began noticing that my left hand was less coordinated than my right, and that it was difficult to perform this task.

During this same time I was going to physical therapy for TMJ symptoms. The therapist noticed my left arm trembling when I did push-ups. She asked why it was happening and I told her I had no idea and told her my other symptoms. She had me lie on the table and moved my arms and legs while telling me to let them go limp. Then she sat me up and told me I needed to see a neurologist. I asked why and she said she noticed some differences and I needed to get it checked out.

Laura at the top of Craggy Pinnacle in Buncombe County

These were my first symptoms of young-onset Parkinson's disease when I was 40 years old. Two years later I got the diagnosis in July of 2016. By this time my left arm had quit swinging when I walked.

I have no family history of this disease, and because of my age they monitored me for a year because there were no other signs on the MRI scan. The neurologist told me that Parkinson's would only decrease my life by one month compared to others and that I would not die from Parkinson's, but with it.

> Knowing there were resources gave me something positive to focus on; this is when I learned there were ways to manage this disease and be proactive.

I was given a medication, and when I asked what I could do to fight this disease they said to eat healthy and exercise. I was not given any other information about Parkinson's or any referrals for services. At the time, I thought I would rather have a disease that would kill me than slowly have to watch myself deteriorate. I had no idea what to expect because I didn't know anything about Parkinson's and had not met anyone who had the diagnosis.

To make matters worse, two weeks later, my relationship of almost 10 years ended (for several different reasons). I was pretty depressed for about three months and didn't know where to turn. I pursued having a DaTscan because I was in denial and wanted to show that I couldn't have this disease. The results from the test were "consistent with someone in the early stages of Parkinson's disease."

continued next page

Laura's Journey, cont. from previous page

My mother had told her friends about my diagnosis, and luckily one of them knew someone with Parkinson's disease and asked him to call me. Connecting with PSG-AVL member Steve Miller was a game changer for me! He told me about Sean Simonds' boxing program at Movement for Life, the support group, and the pole walking group.

Knowing there were resources gave me something positive to focus on; this is when I learned there were ways to manage this disease and be proactive. I started participating in the pole walking group and met with Sean. He was very encouraging and helped me feel more confident that there were things I could do to fight back against this disease and its progression. Even though I was much younger than everyone else in the pole walking group, they were welcoming and made me feel a part of the group.

Another resource which really helped me was connecting with others with Parkinson's my age on social media. I joined several Facebook groups and an online support group through the YOPD network, and have connected with people from all over the U.S. and even other countries. I have learned more from talking to others with the disease than anywhere else.

> Getting this diagnosis has helped me to not sit on the sidelines in life and be bolder in taking chances, and has helped me meet so many wonderful people.

Today my symptoms are stiffness, slowed movement, muscle cramping, insomnia, anxiety, soft speech, and difficulty with focus. I have been working for the state of North Carolina as a licensed recreational therapist for 28 years at an alcohol drug abuse/psychiatric treatment center. Work is getting harder due to fatigue. When my medication wears off, my symptoms come back.

Laura paddleboarding at Lake Jocassee

Stress also makes my symptoms worse, and I definitely have job stress and worry about my future. I have to wake up in the morning, take my medication and lie back down until it starts working so I can start my day. I am also having to be more thoughtful in how I spend my time and not plan too many activities in one day, or set aside time for a rest break.

I am in the process of applying for the disability income plan through my health insurance to see if I can retire early and find part-time work. I currently live with my parents, which helps me pay for different therapies and my gym membership; I am so thankful for that.

Therapies and exercises I find helpful are boxing, yoga, strength training, Pilates, acupuncture, speech therapy, massage, indoor rock climbing, and deep breathing/meditation.

continued next page

Laura's Journey, cont. from previous page

Advice I would give others is to be your own advocate, learn from webinars from trusted foundations and advocacy groups, talk to others with the disease, and stay as physically active as you can. Find enjoyment through a hobby or skill you enjoy. I love music and find that going to see live music events gives me a natural boost of dopamine.

Laura getting to meet her favorite singer, Michael Franti

There has been some research showing that loneliness can be a predictor of faster progression of chronic illness; staying social keeps your mind off of yourself. Thus, I am very grateful to have so many encouraging and supportive friends and family.

Being single and younger with this disease is extremely difficult. There is so much uncertainty, and I have been forced to face many decisions earlier than most.

However, having a chronic illness has helped me appreciate every day and to not take things for granted. Getting this diagnosis has also helped me to not sit on the sidelines in life anymore and be bolder in taking chances, and has helped me meet so many wonderful people with and without Parkinson's disease.

Resources

Laura was kind enough to share these links to some of the social media groups she mentioned getting so much out of.

Young Onset Parkinson's Network https://yopnetwork.org/

Facebook groups

STRONGHER: Women Fighting Parkinson's
https://www.facebook.com/share/7PsmFxteefr1PeK9/
*for women with Parkinson's only

YOPD Women Unite
https://www.facebook.com/share/h9sS1DE8t4KXczwR/
*for women with YOPD only

Parkinson's Alternative Healing
https://www.facebook.com/share/ZhvFzRWYs6GxfumX/
*for PwP's, caregivers, and supporters

A rare native of Asheville, Laura Anderson attended Western Carolina University where she attained a bachelors of science degree in recreational therapy. She has worked as a recreational therapist for 28 years at JFK Alcohol Drug Abuse Treatment Center in Black Mountain. Her hobbies include hiking, concerts, playing recreational sports and games with friends, indoor climbing, and family gatherings.

Our Animal Companions


Ozzie, a ragdoll cat who sheds like crazy...


Murphy, 9-month-old miniature Schnauzer and runt of the litter


Boudreaux, a mix of poodle and Coton de Tulear - the softest animal on the planet!

The three pets belonging to member Terry Kirby and his wife, Lynn.

by Jane Rigot

In this issue, we are discussing the benefits of owning and living with pets for those with Parkinson's, featuring some of our Support Group members and their favorite furry friends – from simple lap cats to walking companions to a service dog.

Dogs
Dogs, especially, are always overjoyed to see their "person" return home – whether it is after one hour of separation or 8 hours. For a dog, it means a treat, a walk, or fetching a tennis ball. For a PD patient, it means going outside, getting active, and meeting other people. Stress, depression, and social isolation are experienced by many PD sufferers, but interacting with others on a walk, especially other dog walkers, can help combat a lot of those symptoms.

Even if you've stayed inside most of the day, it's difficult to ignore a dog who brings his leash up to your chair or drops a slobbery ball in your lap. It's time to go play!

Thirty minutes of exercise per day can help alleviate stiffness and boredom, plus maybe the added benefit of weight loss. And having had a good round of exercise can help with other Parkinson's symptoms, such as insomnia and sleep issues.

In addition, reduced health risks have been associated with diseases including coronary heart disease, osteoporosis, and diabetes.


Wilson the golden retriever, teaching puppy Viva how to get treats from Mama and Papa (Linda and Rick Pyeritz)

continued on next page

Animal companions, continued from p. 7

Left to right: John, Lola, Gus, and Chuck

"**Lola** is 16 years old and **used to be the sheriff of the street** in our neighborhood at the foot of Chimney Rock Mountain. She was a free-range dog, getting treats from all the neighbors. **Now she has retired** and is enjoying more well-earned treats.

Gus was adopted 4 years ago and is 6-7 years old. **He joined us in singing Happy Birthday** at a friend's house last year! We didn't even know he was a singing dog!"

--Chuck Horton & John Wilkerson

Before you run out and adopt a dog, however, you should be aware of any physical limitations that could cause you to lose your balance or fall. Always follow the advice of your doctor about the advisability of dog walking. The following article gives several good pointers: https://www.parkinsonsecrets.com/blog/2021/7/28/tips-for-walking-your-dog-if-you-have-parkinsons-disease-5hknt

This article was inspired by Ed and Mary Horton's dog, Rory. It's important to remember that your pet can also be a tripping hazard!

Ollie

Our watchdog

"**Ollie**, our rescue parti miniature poodle.

The best **'Velcro' dog** ever!"

--Rich & Barbara Laibson

Service dogs and Parkinson's

When Les Vann moved to this area to continue his long career in broadcast journalism, he did not expect to retire so soon. But his Parkinson's diagnosis changed that, and two years ago, he obtained a service dog, Dale, a 4-year-old English lab, through the Eyes, Ears, Nose & Paws organization near Chapel Hill, NC. Dale has been his constant canine companion ever since.

Obtaining a service dog is not a quick process. A dog is not ready to join a new home until it has been thoroughly trained by several teams of people, which can take up to two years. There is intensive training not only on the dog's part, but also on the prospective owner's end.

Les Vann and his service dog Dale at an Asheville Tourists game

continued on next page

Animal companions, continued from p. 7

Service dogs and Parkinson's, cont.

The cost upfront can be considerable as insurance does not cover service animals. In addition, anyone who has had a pet knows there are always vet bills.

When Les and his wife, Shannon, were ready to adopt, they had to follow a detailed application process. Once the application was submitted and a match was made, which can take many months, there was a two-week eight-hour-per-day training session in Chapel Hill. The training included academic information, socializing, and information about the breed of dog.

Some dogs are trained as mobility service dogs and others as medical alert dogs. The latter are valuable for those with diabetes and other diseases that a dog's sensitive nose is trained to pick up.

Some of Dale's duties include bringing Les his clothing in the morning, piece by piece. If Les falls, he sends Dale for his wife or son, or any other time Les says "Go get Shannon." And he accompanies him when he walks.

It's important to note that service animals are not pets, and they take their "jobs" quite seriously. However, not all of Dale's time is spent working.

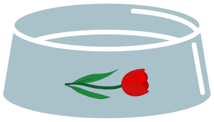
Left to right: Les Vann, Dale, and wife Shannon, riding together in a pedicab in New York City

On a trip to New York City to see the musical "Hamilton" and the Tina Turner Show, Dale got to attend and spent the time underneath Les's and Shannon's chairs, unbothered by the loud boisterous music and noise! Their NYC transportation included both taxis and a pedicab, where Dale hopped up on Les's lap and they waved at passersby. Dale also likes a bit of fetch now and again for exercise.

Les can't stress enough how calm and well-behaved Dale is. "Dale is the most highly trained dog I've ever had, and I've had dogs my whole life."

For a wider scope in locating a nonprofit that will help train and place a dog, Assistance Dogs International (ADI) is considered the overall authority for information, legal issues, and education. They recommend doing a lot of research, and if a need for a service dog is anticipated in the patient's future, it is well to start planning in advance, as the supply is limited.

For more information, go to the Eyes, Ears, Nose, & Paws organization's website at EENP.org, or to Assistance Dogs International at https://assistancedogsinternational.org/.



Cats

Cats provide some of the same benefits for Parkinson's patients as dogs (although they're not too great with chasing tennis balls… and leashing a cat?!). However, cats are typically more sedentary and might be a better fit for those whose balance won't permit extended walking or other active exercise.

continued on next page

Animal companions, continued from p. 7

Cats, cont.
But they still expect you to do their bidding – as the saying goes, dogs exist to please their owners, while cats expect their owners to be their servants. As a cat servant myself, I have experienced cat meows many times that awaken me at sunrise with a “feed me” alert.

Cats are also great stress relievers and their purrs show their gratitude for your attention.

* * * *

“This is **my sweetie Mia**, a rescue kitty. We bonded the first day by cuddling on the couch to take a nap. A friend describes our connection as **‘heart-to-heart’** because of how she lies across my chest and rests her head on my shoulder. She also **loves to be held like that while I dance around** and sing to music. I was disabled by Lyme disease. When I have been ill, she's only left my side to eat or do her business and comes right back. She is smart as a whip and uses her front paw to tap on me to get my attention and then has very specific looks and sounds to communicate what she wants. I believe **we’re a match made in heaven**.”

--Tess Burton

As we can see from the stories and photos of our furry friends, they hold a very special place in our lives. It can be a big decision to invite a cat or dog into our homes, but the joy, the excitement (sometimes unplanned), and the many benefits they bring make it worthwhile for many people to take on the extra responsibility.

THE CATS BEHIND THE NEWSLETTER

photo: Jane Rigot

Jeeves the 20-year-old tux cat hard at work supervising the newsletter editor.

Thomas the tabby assisting the assistant editor.

photo: Kate Rigot

For more information

[Choosing the Perfect Pet for Parkinson's](), from parkinsonsdisease.net

[Tips for walking your dog if you have Parkinson's disease](), from Parkinson Secrets

[Here’s Why You Should Consider Getting a Dog](), info on benefits of dogs for PD, especially service dogs and emotional support animals, from Parkinson’s News Today

[A Helping Paw for Parkinson's](), from the Davis Phinney Foundation

[How to Manage Parkinson’s Disease: Lessons From My Cat](), from Parkinson’s News Today

[How Her Cat Saved Sierra from a Parkinson’s Freezing Episode](), from PetHealthNetwork

AD SPACE

CHOICECARE
YOUR WAY

Elder care in western North Carolina

Choice Care Your Way is a caregiver registry providing high-quality matches of companions and caregivers to clients who need one-on-one care at home, in assisted living communities, during hospital stays, or wherever needed.

Serving Asheville, Hendersonville, Brevard, Weaverville, Black Mountain, and surrounding communities

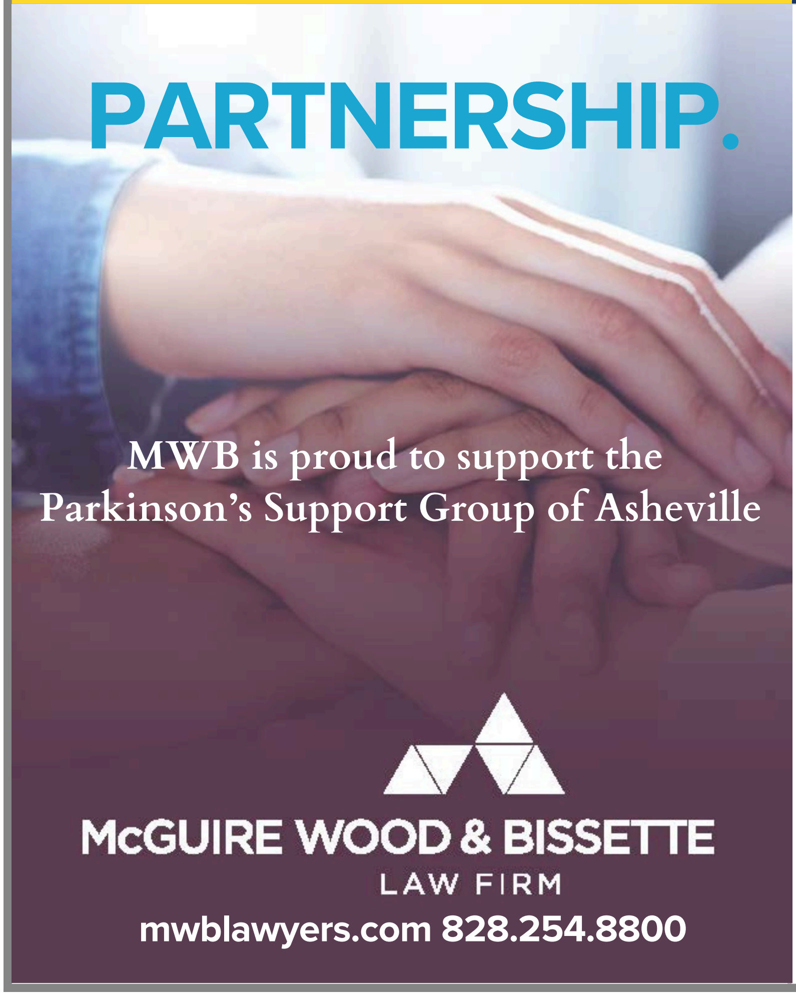
828-772-4714
choicecareyourway.com/
info@choicecareyourway.com

FYZICAL®
Therapy & Balance Centers

OUR TEAM IS PROUD TO OFFER:

- Balance Therapy
- Vestibular Rehab
- Pelvic Health
- Neurological Rehab
- Pain Management
- LSVT BIG Therapy

fyzical.com/western-nc



PARTNERSHIP.

MWB is proud to support the Parkinson's Support Group of Asheville

McGUIRE WOOD & BISSETTE
LAW FIRM
mwblawyers.com 828.254.8800

Mountain Area
Premier Care Navigation

Lisa Laney, MSW, CMG
Owner, Mountain Area Premier Care Navigation

Providing Guidance and Solutions During the Challenging Times of Aging

As advocates for aging adults, Mountain Area Premier Care Navigation (MAP CN) care managers are compass creators for seniors and their families. Tapping into several decades of experience with extensive knowledge of local and national resources, Aging Life Care™ Managers create a successful care map for each client based on their unique needs.

828-772-0002
PremierCareNavigation.com
info@premiercarenavigation.com

Support Group Contact Info

Address

Parkinson’s Support Group of Asheville
825 C Merrimon Ave.
PMB #327
Asheville, NC 28802

Website

parkinsonsavl.org

Phone

828-579-7897

Email

parkinsonsavl@gmail.com

Donations

Send donations through Square:

Donate

Group Leadership

Board
Chris Simpson (Chair)
Bob Pettigrew
Ruthy Fricke
John Matheson
Linda Nelson
Paul Ormond
Lisa Laney

President
Chris Simpson

Vice President
[Vacant]

Treasurer
Gary Forell
psg.avl.treasurer@gmail.com

Assistant Treasurer
Terry Kirby

Secretary
Bob Pettigrew

Program Committee
Mike Horak (Chair)
Lisa Laney

Marketing Chair
Ben Elderd

Newsletter Editor
Jane Rigot

Newsletter Team
Kate Rigot
Sean Simonds

Outreach & Media Chair
Jody Watts

Exercise Opportunities Chair
Steve Miller

Membership Chair
Lisa Simpson
psg.avl.membership@gmail.com

Chat & Chew Chair
Mauri Heim

**for group leaders and officers who don’t have an email listed, please email parkinsonsavl@gmail.com

**To contact someone from the group by phone, please call 828-579-7897

HIDDEN TULIPS

Did you find the hidden tulip in the last issue? (Hint: It was on p. 2.)

Take a “paws” and try to sniff out this month’s tulip!