

# PARKINSON'S SUPPORT GROUP OF ASHEVILLE

"You are not alone"

<http://www.parkinsonsavl.org>  
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## NEWSLETTER NOV/DEC 2024



## IN THIS ISSUE:

### UPCOMING MEETING

\*1st Tuesday of the month

10:00am

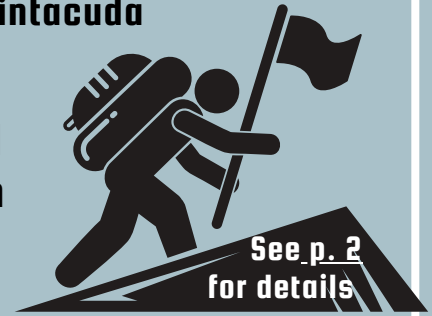
Groce United Methodist Church

Tuesday, November 5

Speaker: local mountaineer

Lucretia Pintacuda

\*no general  
meeting in  
December



### ANNUAL HOLIDAY PARTY

Scheduled for Dec. 3, but  
due to hurricane damage,  
venue unable to host.

**\*\*STAY TUNED FOR INFO\*\***

### VETERANS AND PARKINSON'S

Of the 1 million people with Parkinson's in the US, 110,000 of them are veterans. Here are some of the many resources for the veteran community:

- The VA maintains six [Parkinson's Disease Research Education and Clinical Centers](#) (PADRECCS). VA equivalent of Parkinson's Center for Excellence.
- The Parkinson's Foundation, which has a formal partnership with the VA, maintains a [Veterans & Parkinson's](#) resource site.
- Congress recently passed the [PACT Act](#), which greatly expands healthcare and benefits for many veterans.

See [p. 5](#) for full story

### BEERS AND CHEERS

(3rd Thursday of each month)

Thursday, November 21

&

Thursday, December 19

5:30pm

Highland Brewing  
12 Old Charlotte Hwy



# November meeting: Trekking Upward

## Lucretia Pintacuda on living a vibrant life with Parkinson's disease

Reading [Lucretia Pintacuda's blog](#) on her successful summit of Mount Kilimanjaro to raise money for Parkinson's research last August, one can't help but be inspired by the local hiker's perseverance, tenacity, and determination.

"I think about my climb almost every day of my life," [Pintacuda writes](#). "My reflections vary from day to day. Sometimes I think about the beauty of the natural features in the four climate zones we had to trek through... but at other times I reflect on how arduous the week of camping in small tents, using primitive toileting equipment, sleeping on a thin pad and dealing with the ever present dust was."

Pintacuda, a western North Carolina native diagnosed with Parkinson's in 2017, will show photos and share her personal story during the November 5 meeting of the Parkinson's Support Group of Asheville. Her account will detail how she was selected to be part of the Michael J. Fox Foundation's Kilimanjaro team, how she prepared for the difficult climb, how she got to Africa, and what she discovered about herself and others.

Mount Kilimanjaro is a dormant volcano in Tanzania. At 19,341 feet, it is the highest mountain in Africa and the highest free-standing mountain above sea level in the world. Pintacuda writes that the trip also afforded the opportunity to bond with the other eight climbers, which she affectionately calls the "Kili 9." This group of hikers [was honored in April](#) by the Michael J. Fox Foundation for collectively raising more than \$150,000 for Parkinson's research.

"People have been very receptive to my story and have been very supportive," Pintacuda writes. "I will continue to advocate for those affected by Parkinson's disease... It has been an incredible year of

life changing experiences. I will continue to live life fully and vibrantly as long as I can. I just need to remember to put one foot in front of the other and keep going."



Mount Kilimanjaro. Photo: Lucretia Pintacuda



Asheville resident Lucretia Pintacuda

I will continue to live life fully and vibrantly as long as I can. I just need to remember to put one foot in front of the other and keep going.

--Lucretia Pintacuda

# TUESDAY NOVEMBER 5



November 5 is election day. Vote early and attend the Parkinson's Support Group of Asheville meeting, beginning at 10 a.m. at Groce United Methodist Church, at 954 Tunnel Road in Asheville. There will be social time with food and coffee and a short business meeting followed by Pintacuda's presentation. The meeting room is handicap accessible.

**Reminder that there is no meeting in December.**

## PSG-AVL members represent at Fox Foundation's Parkinson's IQ You event in Charlotte



PSG-AVL members at the Parkinson's IQ + You event in Charlotte. Left to right: Chuck, Ed, Mary, John, and Laura

At least five members of the Parkinson's Support Group of Asheville attended the Charlotte, NC installment of the Michael J. Fox Foundation's popular [Parkinson's IQ + You](#) event in October.

The yearly in-person event is aimed at people with Parkinson's and their friends and family, and includes educational sessions and a resource expo.

Attendee and PSG-AVL member Laura Anderson noted that the content of the sessions "reinforced the need for physical activity to help manage symptoms" and "emphasized the importance of the [Fox Foundation's] [PPMI study](#) and of participation in clinical trials." Another session covered new therapies and treatments being researched.

One of the moderators for the summit was [Jimmy Choi](#), a long-distance runner and member of MJFF's Patient Council who competed in American Ninja Warrior in 2017 years after being diagnosed with YOPD. Laura said she was excited to be able to meet Jimmy because she's a huge fan of his and follows his journey online.

Dates and locations for the 2025 round of Parkinson's IQ + You events have not yet been announced, but those who missed out on this year's summit can catch a talk by one of the event's panelists at our upcoming group meeting November 5th ([see p. 2](#)). Asheville resident and Team Fox member [Lucretia Pintacuda](#), who was part of a group of nine people who climbed to the summit of Mt. Kilimanjaro last year as part of the MJFF's fundraising and awareness efforts, joined other advocates for the "Turning Education Into Action" panel.



Laura with Jimmy Choi

### Annual Holiday Party

As of right now, our annual holiday party is scheduled to take place on **December 3rd**.

However, due to lingering hurricane damage, last year's venue will be unable to host. **Stay tuned for details.**



### Small Group Meetings

Just a reminder that the meeting schedules and/or locations for many of our [small groups](#) (for PwP and for care partners) have been disrupted by the aftermath of Hurricane Helene.

Check in with your small group leader, and keep an eye out for details in future installments of our new monthly **Happenings email update.**



## Anchors Away

by John Matheson

A native North Carolinian, my journey began when I matriculated at NCSU for my undergraduate degree and received my DDS from UNC in 1969, after which I began my first duty station for the U.S. Navy in Orlando.

After 10 months, I was transferred to the Republic of Vietnam. While there, I served with IV Corps in a barracks ship, ending up in Dong Tam in the Mekong River Delta. I was then transferred in country to Da Nang in I Corps. I was released from active duty in 1971 and began private practice in Asheville.

Not being ready to settle down, and believing that the biggest adventure for me was to frequent the Tasty Freeze for dessert, I requested recall to active duty, as well as augmentation and specialty training. My first duty station after recall was at the US Naval Academy. That was followed by a 4-year intensive course in Oral and Maxillofacial Surgery, with training in caring for the war wounded, birth defects, prosthetic handicapped and routine oral surgical care.

On my next assignment, the aircraft carrier USS Independence (CV-62), I spent two years as department head. The first year I spent 51 days in my home port, Norfolk, VA, leaving my wife, Lynne, to assume the role of “primary family leader,” a Navy wife.



*John and Lynne and their son*



*The Lone Sailor statue in DC*

The bulk of the rest of my naval career was spent at the naval hospitals in Newport, RI and Portsmouth, VA. At Newport, I served as a Director of the Hospital and had oversight of the pharmacy, lab, radiology, physical therapy, and ancillary services, and at Portsmouth I was promoted to Department Head and Director of Training. I also was part of a 7-month humanitarian mission to the Philippines and South Pacific on the USNS Mercy, and served in the Gulf War in [Fleet Hospital 5](#) for seven months (1990-91) in Al Jubail, Saudi Arabia. Following the conclusion of the Gulf War, I returned to Portsmouth Naval Hospital.

My retirement from the Navy followed in 1992, and I returned to Asheville and private practice until full retirement in 2016. During my time in Asheville, I led dental teams three times to Bolivia and 15 times to Honduras. This humanitarian activity began with weekly civic action clinics in Vietnam

My Parkinson's disease was diagnosed in Sept./Oct. of 2023 and may be attributable to Agent Orange exposure in Vietnam and/or the pollutants I breathed during my time in Saudi Arabia. I have been placed on both the Agent Orange Registry and the Gulf War Registry.

Although my Navy career was rewarding in many ways, it has left a lasting impact on me and my family.

You can read more about Agent Orange exposure in Vietnam veterans on [p. 5](#)

*Capt. John Matheson (USN-ret.) was born in Asheville and lived in Brevard through high school. His US Navy career as an oral and maxillofacial surgeon spanned two wars, two ships, four clinics, and four hospitals. He retired from the Navy in 1992 and was in private practice in Asheville until 2016. John joined our Board of Directors this summer.*

# Veterans with Parkinson's Disease

by Jane Rigot, with Kate Rigot

While much is yet to be proved conclusively as to the causes of Parkinson's disease, both genetics and the environment – and the interaction between the two – are considered to play important roles in its origins.

Those serving in the military are subject to several different occupational hazards known to be linked to Parkinson's, from exposure to toxins and other environmental factors, to head injuries. Parkinson's rates are higher among veterans than among the civilian population. Of the 1 million people in the US with Parkinson's, an estimated 110,000 of them are veterans, who make up only 6% of the population.

For this "**Veterans Day edition**" article, I contacted three members of our support group who are veterans, and asked them to relate their experiences with Parkinson's.

## Agent Orange

Agent Orange is a potent herbicide that was used as a defoliant during the Vietnam War between 1965 and 1971, to expose the enemy within the thick jungles and to destroy their food crops.

In addition to the ecological and agricultural effects of Agent Orange, the mixture contains chemicals called dioxins that result in a wide array of health problems, from birth defects to later development of Parkinson's disease, certain types of cancer, and more.

The VA estimates at least 2.6 million vets were exposed to Agent Orange, primarily in Vietnam, but also in the Korean DMZ and while serving in both military and civilian locations where the product was stored. Even service members who were not right in the jungles of Vietnam were affected, including Navy personnel serving on vessels off the coast and medical providers treating soldiers wounded in the jungle.



You can read Dr. Matheson's full story in his own words on [p. 4](#)

One of our group's board members, **Dr. John Matheson**, is a retired Navy oral surgeon who served between 1969 and 1992. Although he is only recently diagnosed, his Parkinson's journey began, unbeknownst to him, when he was exposed to Agent Orange in Vietnam, and later on when he was exposed to sand, dust, and particulates while serving in the Gulf War (exposure to burn pits in the Gulf War and the Southwest Asia Theater of Operations after September 11 has also been linked to Parkinson's).

## Camp Lejeune, TCE, and other toxic exposures

Marine Corps Base Camp Lejeune is a 246-acre training facility on the coast of North Carolina. Built in 1941, it continues to provide housing and training to both civilians and the military. Between 1953 and 1987, a toxic chemical called TCE, used to degrease engine and machine parts, as well as benzene used in fuel oil and other volatile organic compounds, were stored in and subsequently leached from storage tanks on the base. During this same time period, a dry cleaner located just off the base was improperly disposing of a similar chemical called PCE, which also leached into the groundwater.

Research would eventually show that exposure to these chemicals - whether directly from working with them, or from drinking water or breathing air contaminated with them - increase the risk of various cancers and diseases, among them Parkinson's disease.

**continued on next page**

## Veterans, continued from p. 5

### Camp Lejeune, cont.

A [2023 study](#) established that those who served at Camp Lejeune between 1953 and 1987 had a 70% increased chance of developing Parkinson's over those from comparable bases.



PSG-AVL member Dr. Mike Grenauer (USN-Ret.)

PSG-AVL member **Dr. Mike Grenauer** is a retired Navy officer (1972-1996) who served as the commanding officer of a Marine Corps field hospital at Camp Lejeune in the early 1980's. While there, he was exposed to the base's contaminated drinking water.

"It took 30 years before the first tremor symptoms began," he says. "I was diagnosed with Parkinson's disease in 2016."

Another of our members, **Bill Sbrocco**, might be retired from the Marine Corps, but he says he'll always be a Marine! He served in the Corps from 1971 to 1991 in the aviation division, and worked in operations and maintenance and as an administrative officer. He retired as a Lieutenant Colonel.

During his career, Bill lived in Washington, DC and in Okinawa, but mostly at Camp Lejeune. He, too, was exposed to the base's toxic water during the 14 years he was stationed there, as well as the several years he lived there as a child. His diagnosis with PD came two years ago, although he'd had symptoms for five years prior to that. He was diagnosed by a civilian doctor, but has since transferred his care to the staff neurologist at the VA hospital in Asheville.

Exposures to toxic substances such as TCE are not limited to Camp Lejeune, as they have been commonly used on bases throughout the country. Senator [Johnny Isakson](#) (GA) had to resign in 2019 due to Parkinson's and renal cell carcinoma (another condition associated with TCE exposure). Isakson had served in the Georgia Air National Guard in his early 20s during the time when the Air Force used TCE to degrease airplanes, and worked on bases that may have been contaminated with it.



PSG-AVL member Bill Sbrocco (USMC-Ret.)

Additionally, an estimated 10 million civilians worked with these chemicals during the 1970's, including mechanics, printers, painters, and, notably, those in the semiconductor industry.

### Head injuries

Most of us know that head trauma can cause Parkinson's, and you hear about this a lot with former boxers, football players, etc. But many veterans experience head injuries too, often from explosions and other hazards of the job.

As the authors of the 2020 book [Ending Parkinson's Disease: A Prescription for Action](#) state, "Traumatic brain injury adds to the risk of Parkinson's among veterans, many of whom have already been exposed to the pesticide Agent Orange and chemicals like TCE." They also stress the importance of equipment and procedures focused on preventing brain injuries among military personnel as much as possible.

In 2013 the VA [expanded its benefits](#) for veterans with Parkinson's who had a service-connected TBI.

### Caring for our veterans

All honorably discharged U.S. veterans who served for at least 24 months under most circumstances are eligible for health care through the VA, once they register with the VA. Additionally, veterans who sustain injuries or other health conditions resulting in some amount of disability as part of their service are eligible to receive a certain amount of benefits going forward.

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## Veterans, continued from p. 6

### Caring for our veterans, cont.

Normally, in order to receive VA disability benefits, a veteran needs to prove that his or her disability was service-connected. This includes Parkinson's, which may not develop until years or even decades later. However, the VA "presumes" that if the service occurred in a specific location during a designated period of time, certain associated conditions automatically qualify them for benefits.

For veterans who served in the Vietnam War or in the Korean DMZ, there are more than 20 presumptive conditions, [including Parkinson's](#). Parkinson's is also one of the presumptive conditions for those who served at Camp Lejeune between 1953 and 1987.

Fortunately for veterans with Parkinson's – whether their condition is service-connected or not – the VA has positioned itself as a leader in Parkinson's healthcare and research. In 2001, the Veterans Healthcare Administration established six regional centers called [PADRECCs](#) (Parkinson's Disease Research, Education, and Clinical Centers), and in 2006 added more than 50 associated sites, for a hub-and-spoke model of Parkinson's care. The PADRECCs also launched a [National VA PD Network](#) to expand PD awareness and education across the VA Healthcare System for all clinicians who treat patients with Parkinson's.

Additionally, the Department of Defense runs the [Parkinson's Research Program](#), which is the only federally funded program dedicated exclusively to PD research.

Veterans enrolled in the VA healthcare system can call the [PADRECC Network Hotline](#) at 1-800-949-1001 x205769 for assistance accessing Parkinson's-specific healthcare.

### How to

Mike Grenauer offers this advice if you think that your PD may be related to your military service, whether you think it would count as a presumptive condition or not:

- Gather military records and documentation verifying that you served in a location where you were exposed to toxic substances (e.g., TCE, Agent Orange or other herbicides, burn pits, etc.)
- Meet with an authorized and trained [Veterans Service Officer](#) (VSO) to assess your case and receive assistance in filing a claim. Each [county](#) has at least one VSO on staff. They are also found at American Legion, Veterans of Foreign Wars, and Disabled American Veterans posts. There are also two VSOs on staff at the Charles George VA Medical Center in Asheville. There are no fees or expenses for services.

The VA also maintains a formal partnership with the Parkinson's Foundation; the combined efforts of the two organizations aim to "improve the health, well-being and quality of life of Veterans living with Parkinson's disease." The latter maintains a [Veterans & Parkinson's website](#).

### Caregiver Support and Resources

VA hospitals also provide support for those caring for veterans with Parkinson's or other conditions. At our local VA, the Charles George VA Medical Center in Asheville, [support coordinators](#) are available to connect caregivers with resources, including the VA's [Caregiver Support Program](#), which offers clinical services, training and other support, and sometimes even stipends, for those caring for veterans.

Caregivers anywhere – for veterans with any health condition – can also call the [VA Caregiver Support Line](#) at 855-260-3274 to be connected to local and national resources, or even just a listening ear. It also offers monthly educational calls.



continued on next page

## Veterans, continued from p. 7

### Caregiver Support and Resources, cont.

The Parkinson's Foundation also has a website specific to care partners of veterans with Parkinson's at [parkinson.org/living-with-parkinsons/finding-care/veterans/caring-for-veterans](https://parkinson.org/living-with-parkinsons/finding-care/veterans/caring-for-veterans), with materials and links to resources aimed at Parkinson's care partners in general and specifically those caring for veterans, along with veteran-specific information on depression awareness and hospitalization preparedness.



Historically, more attention has been focused on disabling injuries resulting from combat, as well as PTSD. However, exposures to toxic conditions in the veteran population have become much more common in the last half century. Most people don't think of PD as being something associated with those who have survived military service, yet the growing numbers of long-term health issues with PD and other diseases has caused the government to become more engaged. The formation of the PADRECCs, in combination with the emergence of the VA as a center of complete healthcare, provides valuable guidance and support to the military veteran and his or her family.

The United States' obligation to veterans stretches back to President Lincoln's second inaugural address, when he promised "to care for him who shall have borne the battle, and for his widow, and his orphan." This has become the VA's motto, which today has been updated to read: "to promise to care for those who have served in our nation's military and for their families, caregivers, and survivors." We can do no less.

### Resources & More Information

[National Resource Directory](#), database of resources for veterans and caregivers maintained by the Defense Health Agency

[Parkinson's Foundation's page on Agent Orange and Other Toxic Exposures](#)

[VA Public Health website on past water contamination at Camp Lejeune](#)

[Parkinson's Foundation's page on Environmental Risk Factors](#)

[VA Disability Compensation for Veterans with Parkinson's](#), from the American Parkinson Disease Association



**YOUR AD HERE!**



A warm welcome to our newest community sponsor, **Sunrise Speech & Swallowing Therapy**. You may remember Shelby Bjorlie from our January meeting, where she spoke on speech and swallowing challenges and treatment options.

If your business or organization would be potentially interested in advertising in our newsletter, please contact Ben Elderd at [belderd1@gmail.com](mailto:belderd1@gmail.com)



**Sunrise Speech & Swallowing Therapy**



**Shelby M. Bjorlie, MA, CCC-SLP  
LSVT (LOUD) certified therapist**

At Sunrise Speech and Swallowing Therapy my goal is to help you reclaim your voice and keep you communicating out in the world! I also specialize in the assessment and treatment of swallowing and cognitive disorders, both of which can be affected by Parkinson's disease. At Sunrise Speech Therapy, your treatment will be tailored to you as a unique individual, and therapy will be specific to your goals.

**[sunrisespeechandswallowing.com](http://sunrisespeechandswallowing.com)**

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# Support Group Contact Info

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## Donations

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## Group Leadership

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[parkinsonsavl@gmail.com](mailto: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. 10.)

This month's tulip might not be the star of this issue, but see if you can find it!

