VOICES OF RESILIENCE

CONVERSATIONS WITH PARKINSON'S DISEASE WARRIORS, CAREGIVERS, AND ADVOCATES

BOOK I

BY

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Praise

Each chapter in *Voices of Resilience* introduces readers to inspiring figures who share their personal journeys with Parkinson's. Their stories are a blend of challenges, triumphs, and humor, showcasing the unique ways they cope with and adapt to disease. This book not only aims to raise awareness about Parkinson's disease but also to celebrate the strength and creativity of those living with it. The first installment of this series of books offers an insightful and engaging look at the diverse experiences of both men and women at different stages of the condition. This is a passion project for my husband, whose goal is to find a cure for Parkinson's disease.

I am so proud!

—**Grether Ackerman**, Sharon's Daughter-in-Law
See the interview with Grether in Chapter 2.

In *Voices of Resilience*, Dr. George Ackerman once again makes the bold choice to step away from the status quo of pushing the next best medications or citing lengthy clinical studies. Instead, he gives readers a unique understanding of living with Parkinson's disease by sharing candid interviews with those who are currently impacted by this devastating condition. It is through these conversations that readers discover that Parkinson's is much more than a faceless, chronological, neurodegenerative disease without a cure.

Throughout these pages, Dr Ackerman shows that a life with Parkinson's is a journey of self-discovery and patience. It's having the courage to commit to self-improvement and new beginnings. Living with Parkinson's is learning the art of letting go while coming to terms with the challenges of acceptance and compromise. It is discovering the value of being fully present and trusting that the only moment that truly matters—is now.

—**Mick Beaman**, Music Breathes

Within a day of my diagnosis of Young Onset Parkinson’s, I started to trawl social media to see what I could learn. It didn’t take long for me to come across George. He is a 24/7 advocate and one of a kind. He is not only a relentless advocate for a cure but also one of the most encouraging and kindest people I know. This passion is combined with his sharp mind and focus on these remarkable interviews. They are unique, just like George!

— **Carl Beech**, CEO Spotlight YOPD

With all the passion and care that are George’s hallmark, he uses the voices of those directly impacted by this disease to put an exclamation point on raising awareness and advocating for a cure for PD! George is exceptionally eloquent in his pursuit of awareness and passionately in tune with the Parkinson’s community. As individuals challenged with Parkinson’s, my husband and I are so glad to have George on our side, constantly advocating for the benefit of everyone impacted by this disease!

—**Debra Flynn**, Person with Parkinson’s Ambassador and
Florida Chapter Board Member, Parkinson’s Foundation

George has worked tirelessly to bring the world’s Parkinson’s community together in this book through his interviews. Each person featured has a different story with one main theme: provide hope to all of us who are living with Parkinson’s.

—**Glen M. Higa**, President, Hawai’i Parkinson Association,
Certified Personal Trainer, Make It Happen Personal Training

George’s new book, *Voices of Resilience: Conversations with Parkinson’s Warriors, Caregivers, and Advocates,* is a must read.

Dedication

To all those battling Parkinson’s disease
and their families and communities throughout the world
and
in memory of my mother,
Sharon Riff Ackerman,
who fought her Parkinson’s valiantly to the end.

Table of Contents

Introduction

As my mother's symptoms of Parkinson's disease (PD) became more severe (see my previous book *A Son's Journey from Parkinson's Disease Caregiver to Advocate: In Memory of My Mother Sharon*), I knew I not only wanted to do everything I could to help her get well, but I also wanted to help others who had the disease. All the professionals told me, "You don't die from Parkinson's; you die with it." They were wrong. Too tragically young, she passed due to PD on January 1, 2020. After she passed, I was all the more determined to do more. So I became a passionate advocate for PD awareness and search for a cure. See my website: www.togetherforsharon.com

This book of interviews aims to raise awareness and hope for a cure for Parkinson's Disease. I contacted individuals worldwide to obtain the interviews because PD does not discriminate and affects individuals, families, and communities worldwide. I believe we must be family in this fight for a cure. When I learned that approximately 1 million individuals are diagnosed in the United States and over 10 million worldwide, I felt that many other journeys needed to be shared. So many inspired me to keep advocating for a cure!

In 2020, I discovered the World Parkinson Coalition (https://www.worldpdcoalition.org/), which holds the World Parkinson Congress. I thoroughly agreed with the mission: “The World Parkinson Coalition® provides the only international forum on Parkinson’s disease that invites all stakeholders to learn about the latest scientific discoveries, medical practices, and care initiatives that improve the lives of people living with Parkinson’s disease. By bringing the full Parkinson’s community together, including people living with Parkinson’s, we hope to expedite the discovery of new treatments for this devastating disease until a cure is found” (World Parkinson Coalition®, 2024).

The World Parkinson Congress is a 4-day event that brings those throughout the PD community together for awareness. I was shocked to find out there are approximately 10 million people around the world today battling PD. I realized at that point it was no longer just about my mother and me … it was about everyone. So I embarked on a mission to ensure such inspiring journeys would be shared so that no one—and I mean NO ONE—ever feels alone. My mother felt alone as someone diagnosed and battling PD, and I felt alone as a caregiver. So I knew I needed to spring into action and share these incredible stories of hope, love, and resilience. These individuals, whatever their roles as people diagnosed, family, caregivers, researchers, or advocates are to me all warriors.

I did and continue to do this all completely voluntarily. We host the website and provide every interview free for the world. All interviewees provided signed consents for use of their words and gave full support, knowing their journey could likely be published and someday reach those diagnosed, newly diagnosed, those living with Parkinson's for years, families, caregivers, researchers, and individuals who want to understand, learn, and help find a PD cure. I spend countless hours and many nights without sleep because I know the importance of this mission and never want anyone to go through what my mother or our family did. However, my mother Sharon lives on through these stories and journeys—and through you.

The interviews I conducted here with many people involved in Parkinson's are from May 5, 2023, to July 29, 2023 and are arranged in this book in different categories. For each individual, a photograph and brief biography appear first, followed by their responses to my questions. In addition, links to their resources and websites are provided.

As you can see from the Table of Contents, the chapters are divided into People with Parkinson's (Chapter 1); Caregivers and Family Members (Chapter 2); Physicians, Scientists, Researchers (Chapter 3); Advocates (Chapter 4); United States Organizations, Foundations for Parkinson's (Chapter 5); United States Organizations for Related Illnesses (Chapter 6); and International Organizations for Parkinson's (Chapter 7). A conclusion and my bio end the book (Chapters 8 and 9).

This is the first book of a series totaling 800 interviews with people involved in PD. In reading the book, of course you can go straight through. Or, after scanning the Table of Contents, choose which category interests you most. In each, every person has helpful, insightful and even inspiring things to say about PD. Some of those interviewed who were diagnosed with PD also have other roles that they are passionate about, such as teachers, advocates, and authors.

Their interviews are not repeated in other chapters; here they speak powerfully about their various roles.

Some interviews refer to events that they are planning to participate in. At the time of publication, these events may have taken place, such as the World Parkinson Congress, Barcelona, Spain, 2023. You can refer to the websites of these for the most current events. In addition, it is possible that some of the linking and contacting information may not work. In such cases, if you want to find out more about the individual, search their name on the internet.

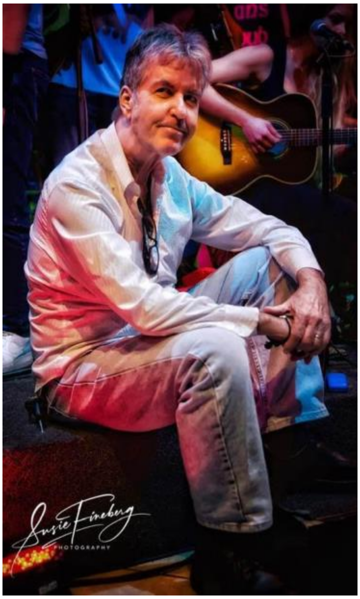
What struck me most about the interviews is that every person who agreed feels passionately about the fight against PD and for awareness and a cure, as I do. They were all remarkably frank and transparent about their struggles with PD, did not let it stop them, and determined to live life to the fullest and use their knowledge and talents for contributing. Their thoughts and expressions moved me greatly, often to tears. I hope these interviews, and each person's passion, creativity, and dedication, inform you and enlighten you, and give you tools you can use to deal with your own or a loved one's or friend's Parkinson's.

Chapter 1

People with Parkinson's

This is the longest chapter in this book, and almost all of those diagnosed were not stopped but have continued with other roles. Each one has participated and contributed to PD awareness, as you will see. When I approached people, I was amazed at the responses—all were very willing to be interviewed and more—candidly to share their stories, information, and resources. And I was very moved by all the responses. These people with PD are stretching themselves. They demonstrate dedication, grit, and a true desire to help others and become voices for PD awareness and resources.

Dan O'Brien, DOB Parkinson's Charity



Dan O'Brien's Biography

In August of 2012 I was diagnosed with Parkinson's disease. After the initial shock wore off, I went to fill the prescription from the neurologist, and with no health insurance at the time, and couldn't believe the cost!

That got me thinking about the people who were in my same situation and how they managed to pay for their much-needed medications, Doctors' visits and living expenses … .

Fast forward to today. A core group of dear friends got together with the goal of helping those less fortunate to cover expenses—and DOB Parkinson's Charity became a reality!

We provide funds for medications, physical therapy, and pretty much anything else that those need who are dealing with this horrible, incurable Disease.

One hundred percent of your generous donations go directly to those in our community who are struggling with PD.

More on the DOB Parkinson’s Charity, Foremost 501(c)(3) Charity in South Florida

At DOB Parkinson’s Charity, we are a 501(c)(3) charity dedicated to providing support and resources to individuals and families affected by Parkinson’s disease. We offer a range of services, including financial support, speaking engagements, and resources to help you better understand and manage the condition.

Please tell me a little about your background and what got you involved with awareness.

I was a professional musician my whole life. After I jumped off a stage during a performance, I came down on my knee and broke my hand. About a month later my finger started twitching.

I had an appointment with a medical doctor, and I was diagnosed around 11 years ago with Parkinson’s disease. He gave me medication to take but with no health insurance, the cost of medications was overwhelming. I was amazed as to how much money it cost. Fortunately, at the time I had the funds, but I started thinking about other people and thought this isn’t going to work. I wanted to make people more aware of what is happening.

That diagnosis has blossomed into a life I never thought I would have, ever. I am grateful, though, because we help a lot of people through the foundation. I want to do this for the rest of my life and take this as far as I can.

I realized there is a struggle for those in the same situation. There are people struggling to pay for medicine or pay their rent. That realization became a driving force for me to create more support. No one is helping those people and that is where we come in.

What is the title of your book and what motivated you to publish?

I have three published books right now (https://www.southfloridaconcertnews.com/post/dan-o-brien-continues-to-strum-a-song-of-hope-for-parkinson-s-patients).

The third was published August 20, 2023, which is the anniversary of the day I was diagnosed, and is called *4015 Days*, which is the number of days since I was diagnosed. This book is more from a caregiver's perspective and how it affects my family, friends, and the musical community—all the people in my life I love.

I play guitar and I have played on stage with some of the best players on Earth. Many people are still constantly calling me and offering their support. It is incredible. I never thought I would be involved with this; I thought it was an old person's thing.

Can you tell me more about the deep brain stimulation (DBS) procedure?

I had DBS surgery 2 ½ years ago. I wish I had done it earlier. DBS is not a cure; it is an effective treatment. I had very bad tremors. Now I have no tremors and I haven't had to take any medications at all since surgery. I do a lot of work with Boston Scientific and have their device in my head. I do not tell anyone to do the surgery or change their mind, I just give my opinion and my experience. I turn off the device to show the effects when it is off. It is not a good sight when I turn it off.

See more research on DBS at
https://www.mayoclinic.org/tests-procedures/deep-brain-stimulation/about/pac-20384562

When did you start playing guitar and become a professional in the music field?

My Mom passed away when I was 12 and that is when I started playing. I met a lot of people in NYC, and it was easy to move up the ladder in the professional field of music. I started at age 18 and have been very fortunate and blessed to have played with many famous musicians. They still reach out to me to check on things. A bunch of local guys is outstanding and do not get the credit they deserve.

Can you tell me more about your organization?

I started an organization years ago but I found myself doing everything so I decided instead to join with other individuals and ***bridge the gap*** for those who cannot afford having Parkinson's disease. You factor in losing your job and the costs of the medications and so much more; it is very difficult. We give money to people to pay their mortgage and many other things and to raise awareness and help people who need it. It is a very expensive disease from caregivers to medications.

At DOB Parkinson's Charity, we understand that every individual's journey with Parkinson's disease is unique. That's why we provide tailored support and quality resources to help manage the condition and improve quality of life. We offer financial support, speaking engagements, and resources to individuals and families affected by Parkinson's disease. We are a team of experts dedicated to providing personalized guidance and support to help individuals navigate the challenges of Parkinson's disease.

What is your passion and how did you get involved in Parkinson's awareness and hope for a cure?

I couldn't really go out there and express my passion in music anymore. Helping the Parkinson's community wasn't something I thought about. I just sat down and started writing. I write something down every single day. I think maybe this is why I got this disease because this is what I am supposed to be doing on this Earth. I am here to raise awareness, and I really do believe I am still here to speak out until we find a cure.

What type of goals do individuals with Parkinson’s have when working with you?

For most people we help, the biggest goal is to not need our help. It is amazing how many people are ashamed to ask or ashamed to get help. The loss of independence and the fact that people want normalcy is what we try to aim for.

What type of training is required, and how long are the programs?

We refer individuals out to programs, but we do not actually have a physical location. I also have given guitar lessons for Parkinson’s patients.

Whether you need assistance with medications, doctors’ visits, or living expenses, we are here to help. We also offer a range of products, including books, videos, shirts, and hats, to help raise awareness and support our mission.

With DOB Parkinson’s Charity, you can rest assured that you are receiving the support and resources you need to live your best life. Contact us today to learn more about how we can help you or a loved one manage Parkinson’s disease.

What would you like to see as a future goal for your organization?

We would like to have one of our charities in every single county in Florida. Then everywhere in the state and then expand around the world. If we can change one area through awareness, then the more people we help, it will spread to other cities and states.

What events do you participate in?

It was in Crazy Uncle Mike’s in Boca Raton, Florida that we had local bands donating their time. See https://crazyunclemikes.com/

How does this also assist the caregivers?

In Holy Cross, located in South Florida, we are setting up something that will be a forum for caregivers, free of charge. My wife will be speaking and talking about her experiences. I would like to have other caregivers also come and speak as well from the caregiver perspective. I feel caregivers in some ways have it worse, and they are ignored. You must educate yourself.

How can someone get in touch? What is your website?

Please visit https://dobparkinsonscharity.com/

Mark Milow, Parkinson's Advocate

Mark Millow's Biography

My background in relation to Parkinson's disease started when my wife and I cared for my grandmother, who had Parkinson's disease and dementia. My grandfather also (both on my mother's side of the family) suffered from PD (both in the '90's). And then in 2020 I began to experience symptoms and was diagnosed in February of 2021 with Young Onset PD (YOPD). After my diagnosis, I became obsessed with finding out more about PD. I created a couple of social media accounts (TikTok and Instagram: @markinthepark21 for both platforms) and began "vlogging" about my experiences, more as a therapy for myself than anything else. But I found that those "vlogs" were helping people through their own journeys.

I began advocating for PD awareness over the next 18 months, which led to the Parkinson's Foundation asking me to join their Ambassador Program, and to be part of their Southwest Chapter Advisory Board. So now I do what I can to be a voice for the PD community, while still working full-time. As an example, near the end of 2022 I had the privilege of joining the good folks at the Michael J. Fox Foundation in meeting with Arizona Representative Debbie Lesko in asking for her support for the "End Parkinson's" legislation that was introduced last year. And now I am working to raise the funds to go to the World Parkinson Congress.

Please tell me a little about your background and what got you involved with awareness.

I was diagnosed in 2021 with PD. When that happened, I really struggled with the "why?" I was always purpose driven, but my mind struggled to put meaning to it. I found by posting online and sharing my experiences that people were responding and finding help or answers going through what they were. Through that I gained a passion for advocacy and speaking out about Parkinson's because I realized how misunderstood many were. I thought I would like to change that. It was therapy for me to talk about what I was going through but in turn I was also helping others.

I created Mark In The Park 21 shortly after I was diagnosed with Parkinson's disease in February 2021. I was searching for information online and I found an entire community. I have also found great purpose in Parkinson's Awareness and Advocacy.

Can you tell me more about your advocacy?

My advocacy started with Tic Tok, Instagram, and a Facebook group. I started posting online things I was learning, things from other Parkinson's patients and caregivers. Caregivers play a large role in the process. I was enrolled in a Parkinson's Foundation "moving day." I was amazed how many people were attending, and it was great to see so many in the Parkinson's community.

I have partnered with the Parkinson's Foundation, and I proudly represent them as a Parkinson's Foundation Ambassador, a Hospital Care Lead, and a Chapter Advisory Board Member. My work with the Parkinson's Foundation and other organizations and individuals in the Parkinson's community spans a myriad of social media platforms. I can be heard on podcasts such as "Two Mikes" and seen on Instagram Lives with professionals across the Parkinson's community. I created this space as a sort of "home base" for the various projects I'm involved in.

What is your passion and how did you get involved in Parkinson's awareness and hope for a cure?

As of late, I have been speaking to long-term care facilities through the Parkinson's Foundation and I do the presentations. I get to meet caregivers, staff, and the individuals with Parkinson's. I really enjoy speaking and working with the Foundation.

What is the biggest issue today in the Parkinson's community?

We need a cure. I love the legislation moving through Congress with the Michael J Fox Foundation. Today there is no dedicated federal funding for Parkinson's disease. I was fortunate enough through the MJFF to be on a call to discuss how important this is for my community as well. I told them the medication has been around for a long time and has negative side effects with prolonged use and discussed many areas the legislators were not aware of. They promised to back the bill and get more involved.

What type of goals do individuals with Parkinson's have when following you on social media?

I believe when people come to my social media pages, they feel positive. I find caregivers and families contact me and ask many questions. They are supported and know others are out there just like them. People have opened and shared their hearts with me. They have literally contacted me, and I have talked for hours trying to provide my experiences so they can also have hope and direction.

One of the biggest struggles is for people newly diagnosed to find resources. Many are told by doctors to take pills and see you in a few months. You walk out and feel lost and do not know where to go, and the resources for individuals are huge. I cater to the young onset Parkinson's crowd and focus on the early diagnosed. I am trying to create a support system for the PD community.

What would you like to see as a future goal for your advocacy?

I am attending the World Parkinson Congress which focuses on Parkinson's as a whole. They bring doctors, caregivers, and individuals with PD all together to network, support, and build relationships around the world. See https://wpc2023.org/

Another goal is improving the information available for the newly diagnosed. I have proposed with the Parkinson's Foundation and more resources for Young Onset Parkinson's.

What events do you participate in?

Parkinson's Foundation "Moving Day," The World Parkinson Congress, Parkinson's revolution (a biking event), and Michael J. Fox Foundation events.

How does your advocacy assist caregivers?

This is a very underfocused section of the Parkinson's community that needs attention. Caregivers are just as important as patients because they bear so much weight. There needs to be more resources, support groups, and focus due to the mental and emotional drain of caring for individuals with PD. I have had several caregivers contact me, but I feel we need to do more, especially as the stages of the disease advance.

How can someone get in touch? What is your website?

You can reach me, Mark, at https://www.markinthepark21.com/

Also at the Congress held in Barcelona, Spain, this coming July as a volunteer to help at the convention.

Philip Ommen, Parkinson Positivity

Philip Ommen's Biography

Philip Ommen is an accomplished professional in the hospitality industry, boasting an impressive career spanning over 35 years. He is currently serving as the CEO of Rubicube Hospitality, a renowned company specializing in hotel and asset management, as well as the managing partner of Rubicube Creative, a global branding and design consultancy firm.

Despite the obstacles posed by Parkinson's, Philip's faith and resilience have enabled him to establish his own hospitality management company. The road has been far from easy, but he remains steadfast in his resolve to forge ahead.

On May 16, 2023, Philip underwent a deep brain stimulation procedure in hopes of improving his condition. As of June 14, 2023, the DBS was activated, and he remains optimistic that this treatment will be successful, allowing him to regain some of the abilities that Parkinson’s has taken away.

Philip’s experiences have ignited within him a passion to spread the power of positivity and inspiration to others. He believes in uplifting those around him and instilling hope in their hearts. Through his own journey, Philip aims to inspire and empower individuals, showcasing the strength of the human spirit in the face of adversity.

Together, let us join Philip Ommen in spreading the power of positivity and inspiration to our fellow beings, lighting the way for a brighter and more resilient world.

Please tell me a little about your background and what got you involved with awareness.

My journey has not been without its challenges. Since 2016, I have been battling Parkinson’s disease, and it took me 3 years to fully accept my diagnosis. However, I consider myself blessed to have the unwavering support and encouragement of my family and friends. Their presence is a constant source of strength and inspiration throughout my journey. Recognizing the power of positive inspiration, I made the decision to fight Parkinson’s with unwavering determination.

Can you tell me more about your advocacy?

I’m deeply passionate about advocacy and making a difference. My journey in advocacy began when I realized the power of spreading awareness and educating others. I believe that by sharing information and personal experiences, we can create a greater understanding and empathy for those affected by Parkinson’s disease.

Speaking of advocacy, let me delve into my work in Parkinson’s awareness. I’m dedicated to promoting understanding, support, and hope for individuals living with Parkinson’s. My advocacy efforts focus on highlighting the challenges faced by those with Parkinson’s and the need for continued research towards finding a cure.

What is your passion and how did you get involved in Parkinson's awareness and hope for a cure?

My passion for Parkinson's awareness stems from a personal connection. I'm personally going through the journey, and it inspired me to act. I wanted to contribute to the efforts aimed at finding a cure and improving the quality of life for those living with Parkinson's. This motivation led me to actively participate in various initiatives and organizations focused on raising awareness and advocating for better resources.

What type of ways do you try to bring positivity to the diagnosis of PD?

In my efforts to bring positivity to the diagnosis of PD, I explore different avenues. I engage in activities that promote a positive mindset, such as sharing uplifting stories, organizing support groups, and participating in events that foster a sense of community and encouragement. By focusing on the positive aspects of life, we can empower Parkinson's fighters to maintain a hopeful outlook and enhance their overall well-being.

What effect can positivity have on an individual with Parkinson's?

Positivity has a profound effect on individuals battling Parkinson's. It can provide them with the strength and resilience to face the challenges of the condition. A positive mindset fosters hope, improves mental well-being, and enhances the overall quality of life. By promoting positivity, we can uplift the spirits of Parkinson's fighters and inspire them to keep pushing forward.

What would you like to see as a future goal for positivity for Parkinson’s?

Looking ahead, my vision for the future of positivity in Parkinson’s is to see it become a central aspect of the support and care provided to individuals with the condition. I hope to witness a shift in the way society views Parkinson’s, where positivity is not only seen as a bonus but as an integral part of the treatment and management approach. By incorporating positivity into every aspect of Parkinson’s care, we can create a more holistic and empowering environment for those affected.

What was the DBS process and how has it changed your life for the better?

“Deep brain stimulation (DBS) is a surgical therapy used to treat certain aspects of Parkinson’s disease (PD). This powerful therapy most addresses the movement symptoms of Parkinson’s and certain side effects caused by medications. DBS may also improve some non-motor symptoms, including sleep, pain, and urinary urgency. It is important to keep in mind that DBS can only help relieve symptoms, not cure or stop disease progression… . It is most effective for people who experience disabling tremors, wearing-off spells, and medication-induced dyskinesias, with studies showing benefits lasting at least five years” (https://www.parkinson.org/living-with-parkinsons/treatment/surgical-treatment-options/deep-brain-stimulation)

The DBS procedure has helped me immensely and I am very grateful for it.

How can someone get in touch? What is your website?

I am on Instagram @ parkinsonspositivity

Ali Blevins, Poets With Parkinson's

POETS WITH PARKINSON'S

thewall.com

Ali Blevins' Biography [Not supplied.]

Please tell me a little about your background and what got you involved with awareness.

In 2017, after more than a year of experiencing a variety of weird symptoms, at the age of 52 I was diagnosed with Parkinson's disease. Fairly devastating news for someone with a passion for the outdoors and who has spent much of her life in the pursuit of physical adventure!

Before the diagnosis I was a primary school teacher. I was advised to try mindfulness coloring to help with my fine motor control and that is when I started drawing and painting. I entered an art competition run by https://parkinsons.art and then began to participate in their poetry section. As a member of that group, I have had work shown in two art exhibitions in London and my poems have been included in a book of poetry. Since then, the poetry section of Parkinson's Art has created their own website. It is run by Nigel Smith, Martin Pickard, Katherina Beyer, and myself.

Can you tell me more about your advocacy?

Poets With Parkinson's is run by Nigel Smith, Martin Pickard, Katherina Beyer, and me. We are a safe place for poets who happen to have Parkinson's. The site is primarily about supporting each other as poets and not so much about advocacy.

Parkinson's disease is a condition in which parts of the brain become damaged over time. Parkinson's disease has over forty recognized physical and psychological symptoms. The disease is progressive and currently there is no cure.

Exercise is the only thing proven to slow down progression of the disease, and I was told to adopt a "use it or lose it" approach.

"That's fine," I thought. "I can do that."

However, there was one part of my body that exercise wasn't helping, and I was referred to a physiotherapist to improve the dexterity and fine motor control in my right hand. Mindfulness coloring was what was suggested, but I soon realized that wasn't for me. Frustrated and bored, I started doodling instead. The doodling led to drawing and the drawing led to painting.

What is your passion and how did you get involved in Parkinson's awareness and hope for a cure?

Creating artwork has been the perfect vehicle for helping me come to terms with having Parkinson's disease. Art enables me to work through my stresses, let off steam, and express how I am feeling. I do not have a particular style; I tend to go where the mood takes me, sometimes fun, sometimes reflective, often quirky. But at its heart there is always narrative, emotion, and a need for movement. My passions are art, poetry, music, and being outdoors.

What effect can poetry have on an individual with Parkinson's?

Since with Parkinson's I first picked up a pencil, I have exhibited at the Reader Gallery in Liverpool and twice at the Oxo Gallery on London's South Bank. In 2021 I was commissioned by Charles River Laboratories to paint a giant hare for Leuchie House as part of their Big Hare Trail, and I had my first solo exhibition at The Barefoot Sanctuary in North Berwick.

What would you like to see as a future goal for your artwork and advocacy?

Ali Blevins Art is my own personal Facebook page. I have been creating consistently since diagnosis. Not all my art is about Parkinson's, but a lot of it is. I try to use it to share my experiences and enlighten people a little about the disease. I have had my work exhibited at the Oxo Gallery in London and have had two solo exhibitions.

I also founded a group called the "Art of Possible Collective" and exhibit regularly with them. These are people who have come to art through either illness or injury. Most of my work exploring Parkinson's is on display at Leuchie House, a charity which provides respite breaks for people with neurological diseases, including Parkinson's.

What events do you participate in?

This year my artwork has been displayed in Leuchie House's Aviemore Room for their 10-year anniversary celebrations, and I am a long list finalist for the Scottish Portrait Fine Art Award 2022. Through auctions, raffles, and art sales I have been able to raise over £10,000 for a variety of charities, including Parkinson's UK, Leuchie House, Shelter, Action Aid, and Help for Heroes.

How can someone get in touch? What is your website?

https://www.poetswithparkinsons.com

Esther Labib-Kiyarash, On Advocacy

Esther Labib-Kiyarash's Biography

I am 48 years old. I have been married for 20 years to my amazing husband and have two children, ages 10 and 11. I grew up in Las Vegas but now live in El Paso, Texas. Professionally I have a master's degree in healthcare administration and am a healthcare administrator specializing in performance improvement, regulatory compliance, and risk management.

Please tell me a little about your background and what got you involved with awareness.

I was diagnosed with Young Onset Parkinson's disease in February of this year (2023) after a 2-year difficult journey to a diagnosis. I became involved with awareness because I did not know very much about Parkinson's until I had it. What I thought I knew was very wrong and different from what it was like. I realized I didn't know anyone with this disease, had been given little information from my doctor, and never saw anyone with tremors in public.

I had a TikTok account, and I began posting about my diagnosis and following people on TikTok there to learn more about my disease. I noticed that I rarely saw people who looked symptomatic; they would say they had a tremor, but I wouldn't see it, and this made me feel very invisible. I started posting about my symptoms and showing my tremor more. This simple act, along with explaining the different symptoms of the disease and how it feels, really resonated with people.

I now have over 1,500 followers and one of my videos has over 125,000 views on TikTok. This video was about my diagnosis, which means many more people now see what this disease looks like and entails. I hope that one day people will see YOPD like other conditions (autism, Tourette's, multiple sclerosis) that have visible motor signs and become more accepting so that people are comfortable in their bodies and live without fear of judgement.

What is your passion and how did you get involved in Parkinson's awareness and hope for a cure?

My passion is improving the quality of life of Parkinson's patients through standardizing the process of informing them of their diagnosis. I also want to make Parkinson's patients more visible and normalize our different body movements (shaking, slowness, speech differences, etc.).

I want individuals to understand what an individual goes through. There are a lot of misconceptions, like we are going to die early. However, it is a chronic disease that progresses over time.

I would see people talking about their experiences, but I did not see people shaking and I was thinking about the differences in individuals who show different symptoms. Once I had the tremors, I understood that people look at you in a different way. I was upset because I felt it is not fair. We have a movement disorder, but people need to see it and be aware and understand it.

I am trying to show how we really look so others are not so surprised or scared.

Can you tell me more about Young Onset PD?

When I was diagnosed, everyone around me seemed baffled and couldn't understand that a person could get PD so young. We must navigate our work and how to explain it to our children, but it makes me hopeful because this is all my children know. I think about how my voice changed when I had my first child. My children grew up with me having this disease, and there is no guidebook as to my health or raising children while having Parkinson's. That scares me the most. Also, healthcare providers need to be more aware and learn more about early onset.

We go through years of misdiagnoses and do not understand the diagnosis, but it is more common than everyone knows. Under 50 is young onset and under 40 is early onset.

What type of impact do individuals with Parkinson's have when viewing you on social media?

That is the most surprising and heartfelt thing—that I can reach and talk to people about my experience. They feel they have someone who understands. When I was diagnosed, I found people to talk to and ask questions about PD. I was happy to find individuals who took time to share their experiences. I spend many hours every day with them because my social media keeps growing and growing from people around the world.

It is satisfying because I have been there, and it is unfortunate sometimes that we must go online since there are many local resources that are not there.

What would you like to see as a future goal for your advocacy?

I would like to continue to reach many individuals through my social media and act as a support through my own experiences and journey with Parkinson’s. I am currently onboarding as an Ambassador for the Parkinson’s Foundation.

How does this also assist the caregivers?

I have had many caregivers reach out to me and thank me for explaining what it is like to have this disease. It is hard for caregivers because they really want to understand, and it is hard to explain sometime. I enjoy sharing my experiences with them.

How can someone get in touch? What is your website?

Instagram @shakyboots1 or TikTok @elabibkiyara

If you had one final statement or quote you could leave for the Parkinson’s community, what would it be?

To the Parkinson’s community I would say this: we need to UNITE! Young and old, demand more! Parkinson’s disease is fast growing unfortunately. Younger people are getting diagnosed every day. Yet for some reason we hide in the shadows. It’s time to stand up, be seen, demand change, more support, more resources, better medications, and A CURE.

Rachelle Smith-Stallman, Dance Beyond Parkinson’s

Rachelle Smith-Stallman’s Biography

Rachelle Smith-Stallman’s passions are dance, choreography, teaching, and performing. She is presently teaching DANCE BEYOND PARKINSON’S and LET’S DANCE. She has a Bachelor of University Studies degree in dance from the University of New Mexico and a Master’s in Dance Therapy (board certified) from Hunter College. She is a New York State Licensed Creative Arts Therapist and a certified IMPROVment® instructor from Wake Forest University. She has participated in many professional development training courses in Dance for PD from the Mark Morris Dance Group in Brooklyn, New York.

Please tell me a little about your background and what got you involved with Parkinson's awareness.

I fell in love with dance in college at the University of New Mexico. My love of working with people and my love of dance naturally led me to get my Master's in Dance/Movement Therapy. I've danced with many different populations over the years, including new moms and babies, children with autism, teens with very troubled lives, alcoholics, and drug rehab people, and now Parkinson's. I participated in many professional development training courses with the Mark Morris Dance Group, Dance for PD, and I also became a certified IMPROVment® instructor about a year and a half ago. This technique blends dance and neuroscience and is a great addition to my many years of dancing. It allows me to give the best class possible for my Parkinson's dancers.

I became involved with Parkinson's because three people who are close to me were diagnosed with the disease.

Can you tell me more about your organization?

I volunteered to teach dance classes to the local Parkinson's community, and soon after, some members were willing to send me to study with the Mark Morris Dance Group, which is very well known for their Dance for PD program. Dance Beyond Parkinson's became part of the Capital District Parkinson's Support Group and Help for PD. The groups provide moral support to people with Parkinson's and their caregivers and acts as a resource center for those who want to live well with PD.

What is your passion and how did you get involved in Parkinson's awareness and hope for a cure?

Dance is one of my passions, of course! And as mentioned earlier, I became involved in Parkinson's awareness because people close to me were diagnosed with the disease.

What type of goals do individuals with Parkinson's have when working with you?

That's a great question! I know every one of my dancers wants to feel alive!!!!! They want better balance, more flexibility, to feel more graceful, and they want to have FUN!!!!!!

What type of training and how long are the programs?

My classes meet for 1 hour every week! We meet once on Zoom and once live in-person at a local fitness center here in Albany, New York.

What effect can Dance beyond Parkinson's have on an individual with Parkinson's?

It's a great mood booster, it's being in the moment, and you mix that together with better balance, flexibility, and feeling more relaxed. It culminates in an overall sense of well-being and accomplishment.

What would you like to see as a future goal for your program?

I recently applied for a grant to choreograph a dance for my dancers, including their caregivers, friends, and relatives. I hope I get it! I would also like there to be enough funding to offer my class in other areas in the Capitol district.

How does this also assist the caregivers?

The caregivers have as much fun in my class as the people with Parkinson’s. We all know that physical activity makes you feel good. Pair dancing, relaxation, and creativity with some great music, and you can’t go wrong! Also, for everyone in the class there’s a feeling that you’re not alone. Everyone is very supportive of one another.

What type of music do you like to play during the lessons?

I play it all—classics, soul, funk, French, Middle Eastern, rock, punk, jazz. I love to listen to music, so my playlists are always different, I’ve never played the same playlist twice in 6 years. I also take requests!

How can someone get in touch? What is your website?

The best way to get in touch would be by email.
rss@nycap.rr.com
You can follow Dance Beyond Parkinson’s on Facebook
https://www.facebook.com/reel/201324002403259
and on Instagram at
https://www.instagram.com/dance_beyond_parkinsons/

If you had one final statement or quote you could leave for the Parkinson’s community, what would it be?

Crank up your favorite music and DANCE! We are all hoping for a cure soon!

Neil Russell, Ran From London to Barcelona for PD Awareness

Neil Russell's Biography

Until 2017, I considered myself an ordinary kind of chap, I have a family and a job, and outside of work my focus was triathlons. Training and competing were a big part of my life. But after the Vichy Ironman, I found training was starting to take over my life. Cutting down training hours I would have more time to spend with my partner Nicky, yet still enjoy the social elements of meeting friends and being outside training. I can't remember the exact date, but around April 2017 I set off from the small village of Broadway with my cycling buddies for a training ride. The weather that morning was perfect for hard, fast riding. My only memory is someone laughing aloud as we set off.

The next thing I remember was lying on the verge of a country lane, choking on blood as it dribbled down my face. Little did I know but my life was about to change forever. I was drifting in and out of consciousness as a helicopter ambulance was hovering above me—it landed in an adjacent field. A doctor and a couple of medics jumped out and ran over to me.

I was then taken to the John Radcliff hospital in Oxford. The next day the doctors told me that I had a broken eye socket and jaw, which would be treated a couple of days later by securing the broken bones with titanium plates. I was also informed that I sustained a brain hemorrhage. On top of all that I had a broken wrist, crushed finger, and broken bones in my right hand.

To this day I can't remember how I got off my bike! My cycling friends said I hit a large pothole. The recovery from the cycling accident in April 2017 was slow and tedious, and I lay in a hospital bed for three weeks. What shocked me was the amount of muscle loss I experienced. I was so weak!

When I first got home, I could not even make a cup of tea or open the fridge door. Both my hands and wrists were still in plaster. Over the weeks and months, I slowly started to get better, and as soon as I could I started to rebuild my strength, with help from Nicky who was immense throughout. Eventually my life started to return, and I had a few issues with my hand and shoulder, and still do, but life still goes on.

I'm 65 and I have Parkinson's. This father of two was diagnosed with Parkinson's in 2018 and is determined to not let the condition define him. I decided to complete this challenge after running from John O'Groats to Land's End last year, raising over £11,000 for both charities.

Please tell me a little about your background and what got you involved with awareness.

On 4 July 2023, the World Parkinson Congress opens in Barcelona. I plan to arrive in Barcelona for this conference just before it starts.

My means of getting there: I am running now and started from London to Portsmouth, took the ferry across to Caen in Northern

France, running through France and over the Pyrenees into Northern Spain where I'll arrive in Barcelona for the opening of the World Parkinson Congress.

I will be running to raise money and awareness for Cure Parkinson's

https://cureparkinsons.org.uk/

and Parkinson's UK https://www.parkinsons.org.uk/

What is your passion and how did you get involved in Parkinson's awareness and hope for a cure?

I wanted to raise funds for the charities to find a cure and let others know who have been diagnosed that exercise and activity can help with Parkinson's and raise awareness of the Congress and prove to myself that I can run from London to Barcelona.

I am determined and refuse to be another victim and give into Parkinson's, which is why I take on an extreme endurance events—to tell Parkinson's that it doesn't have it all its own way and that others can do it.

What effect can running long distances have on an individual with Parkinson's?

1. It's a personal challenge to prove to all, including myself, that I can do it.
2. To raise money for Cure Parkinson's and Parkinson's UK, who support others with Parkinson's and help promote a better awareness.
3. To demonstrate that when you're diagnosed with Parkinson's it's not the end. You can still do amazing things if you believe you can and have the determination.

What would you like to see as a future goal for your running?

Through the challenge I want to show people that if you have Parkinson's, you can keep active and do amazing things. I know that not everyone can or will want to run almost 1,000 miles, but I hope to inspire at least one person to get active, whether that's going for a brisk walk, or a short swim—whatever you enjoy and is within your limits.

What events do you participate in?

World Parkinson Congress opens in Barcelona in summer 2023. See https://wpc2023.org/

More on Neil's Journey

Parkinson's diagnosis

Months before my accident, I started to feel that certain tasks were taking me longer, such as my handwriting, using a knife and fork, and the odd twitch in my hand. But I thought it was just down to getting older. The night I will never forget took place several months after my accident—Nicky was away on business. I was sitting watching TV when out of nowhere my right arm jumped and broke into a continuous tremor that I've lived with ever since. At the time I thought it was a trapped nerve and after a good night's sleep it would pass, but it didn't! After a few weeks, I decided it was time to go and see my doctor. He was very nice and was of the view I was drinking too much coffee and diagnosed an essential hand tremor. So, I reduced my seven to eight mugs down to just two, but it didn't make the slightest difference. My hand continued to tremor.

I also noted that my handwriting was becoming increasingly untidy, and as before I was slower on my right side. The hand tremor continued but deep down I knew something wasn't right. I started to check out Dr Google. My handwriting had worsened; I was having difficulty with smell, taste, and balance. And every time I Googled these symptoms, Parkinson's kept coming up.

I asked my GP to refer me to the John Radcliff Hospital in Oxford who were world class when treating me after my bike accident. I saw the professor of neurology who carried out numerous tests; he then confirmed what I already knew. "I had Parkinson's." My first response to his diagnosis was "Can I still run?" He said "Yes" and went on to explain more about Parkinson's and the positive effect that running and energetic exercise has with Parkinson's.

Although I had known I had Parkinson's, I was still in shock, and it took me a few months to come to terms with it. At the same time, my neurologist advised me I should consider giving up cycling, which I reluctantly did. So, I started running again.

The Parkinson's Effect

I have deliberately made a point of not finding out how the many Parkinson's symptoms can affect you because for me ignorance is bliss. The less I know, then the chances of beginning to imagine symptoms and worry myself are reduced. There are three main symptoms that do impact a lot of people with Parkinson's, but there are over 40 others.

Essentially, Parkinson's develops when cells in the brain stop working properly and are lost over time. These brain cells produce a chemical called dopamine. Symptoms start to appear when the brain can't make enough dopamine to control movement properly. It is a degenerative disease and will get worse over time, and there is currently no cure. My understanding is that a new generation of medication is not far off, but until then … .

There is a side of Parkinson's that's very difficult or nigh on impossible to describe or explain; it's a mental or emotional state that some might describe as depression or anxiety, but it's more than that.

A good friend of mine who has Parkinson's and is younger than me once that "the only people who truly understand Parkinson's are people with Parkinson's." To give you a flavor of how Parkinson's impacts me daily:

1. I can’t write a simple note or message on my granddaughter’s birthday card.
2. I rarely get quality sleep.
3. Carrying drinks in my right hand is a no, no.
4. I have a very limited sense of smell and taste.
5. I’m constantly constipated, so I won’t go into too much detail.
6. I am constantly trying to hide my hand tremor, for fear of what others might think.
7. When I eat dry food like toast, cake, or biscuits, it sometimes is awkward to swallow.
8. I sometimes find it hard to speak.
9. I find it difficult putting a plastic lid on a takeout coffee cup.
10. My coordination can be difficult depending on how tired I am.
11. Falling over is something I must be very careful of, especially when I’m running and tired
12. I become uneasy or panic when travelling on my own. For instance, going into London or any large town on my own on the train I find scary.

When you are diagnosed with Parkinson’s it changes you; some days you’re fine, but occasionally it gets you down. I go through a phase of feeling sorry for myself. Why me? I’m not the same person anymore, I’m different, I’ve changed. I look at myself in the mirror and I see someone I don’t like. This strange person is deadpan, miserable looking, menacing, expressionless. I have a vacant expression in my eyes. A sort of foreboding depression lingers over you, tiredness grips you, the fear of what lies ahead is constantly in the back of your head.

Stages of Neil's Run

Follow along with Neil's run LONDON - BARCELONA (L2B) at https://www.neilstillcan.run/london-barcelona

England

25th May London - West Horsley
26th May West Horsley - Lugashall
27th May Lugashall – Portsmouth

France

28th May Caen - Villers Bocage
29th May Villers Bocage - Flers
30th May Flers - Lassay Les Chateaux
31st May Lassay Les Chateaux - La Chapelle Rainsouin
1st June La Chapelle Rainsouin - Soeurdres
2nd June Soeurdres - Saint Martin du Fouilloux
3rd June Saint Martin du Fouilloux - Vihiers
4th June Vihiers - Bressuire
5th June Bressuire - Beceleuf
6th June Beceleuf - Fontenay
7th June REST DAY
8th June Fontenay - Cherbonnieres
9th June Cherbonnieres - Vibrac
10th June Vibrac - Chalais
11th June Chalais - Villefranche de Lonchat
12th June Villefranche de Lonchat - Duras
13th June Duras - Sermet
14th June Sermet - Port-du Casse
15th June Port-du Casse - Lafrançaise
16th June Lafrançaise - Labastide Saint Piere
17th June Labastide Saint Piere - Verfeil
18th June Verfeil - Soupex
19th June Soupex - Ville Longue
20th June REST DAY
21st June Ville Longue - Bugarach
22nd June Bugarach - Sournia
23rd June Sournia - llauro
24th June llauro - Le Perth’s
25th June REST DAY

Spain
26th June Le Perth's - Vilaur
27th June Vilaur - Girona
28th June Girona - Malgrat de Mar
29th June Malgrat de Mar - Mataro
30th June Mataro – Barcelona!!

How can someone get in touch? What is your website?

www.neilstillcan.run or info@neilstillcan.run
Press https://www.neilstillcan.run/media-coverage

If you had one final statement or quote you could leave for the Parkinson's community, what would it be?

Don't give into Parkinson's. Fight it!

Melissa Marie Livingston, Young Onset Parkinson's Disease

Melissa Marie Livingston's Biography

I was diagnosed in 2020 after a 4-year process in which my doctors chased a multiple sclerosis diagnosis. I was alone when I found out I had PD, and even after I told my family I still felt like I was on an island.

Please tell me a little about your background and what got you involved with awareness.

At just 13, I lost my mother and had to overcome so much though my life. I was diagnosed with Young Onset Parkinson's disease. One of my accomplishments is I have gained over one million views on my #parkinsonslookslikeme hashtag.

Can you tell me more about your advocacy?

I started using my Instagram account as kind of an electronic journal to just express myself regarding my diagnosis and journey with it, thinking that if my words helped even one person then that was pretty cool.

What is your passion and how did you get involved in Parkinson's awareness and hope for a cure?

Around this time last year, I posted about a hashtag I had created and was using to put a new face on the tired old Parkinson's stereotype: #parkinsonslookslikeme, and it resonated with the online Parkinson's community.

So now I spend my time just helping people through their struggles with Parkinson's and try to provide a positive, supportive platform for others.

What type of feedback do you get from your social media followers?

Most are supportive and kind enough to share their experiences with others on the same topic.

What type of effect can your posts and platforms have on an individual with Parkinson's?

I have learned, through feedback, that shared experiences are kind of an equalizer and allow us to give ourselves grace.

What would you like to see as a future goal for your social media?

I'd like to expand my advocacy to mental health and chronic illnesses, not just Parkinson's.

What events do you participate in?

I do the 60 miles challenge with the Parkinson's Foundation as well as collaborate on and help plan events throughout the year with Gray Strong where I am also the social media manager and publish our blog.

How does your social media advocacy also assist caregivers?

Often caregivers tell me that my posts help them understand their loved one's experiences better, particularly if their loved ones are not comfortable with discussing with them.

How can someone get in touch? What is your website?

Missmliv @ Instagram and undeniablyhoneybee on TikTok

If you had one final statement or quote you could leave for the Parkinson's community, what would it be?

Your diagnosis is not the end. It will change your perspective, often in a positive way. With hard work and resilience, you can live a beautiful life with PD.

Megan Taye, YOPD Love Letters

Megan Taye's Biography

Megan Taye was diagnosed with Young Onset Parkinson's Disorder in her 40s, after years of symptoms. When she's not working full time, she loves spending time with her husband and two kids. An advocate at heart, Megan testifies to lawmakers about living with YOPD. She also recently started an Instagram page (@yopd.love.letters) to spread awareness about Parkinson's disease and to connect with other people living with YOPD.

Please tell me a little about your background and what got you involved with awareness.

I was diagnosed with Young Onset Parkinson's disease in my 40s. I'm a wife and mother of two children, working full-time and living a very active life. I am a private person and didn't want to share my diagnosis with others at the beginning. I started a diary of my progression for my children.

Can you tell me more about your organization?

YOPD Love Letters was created to spread awareness about Young Onset Parkinson's disease. I had been creating digital love letters to my family to document my love for them, in the event I may not be able to communicate that to them as my disease progresses. I also hoped it would help my kids understand the reasons their Mom was changing as the years passed. Seeing my family and close friends' emotional reactions to the love letters dawned on me that I could share them publicly, to spread awareness (and as a byproduct, increase visibility and fundraising to speed a cure).

At first my goal was to capture people's attention and awareness, but what I didn't realize was that I would also be attracting many others with Young Onset in the United States as well as around the world.

What is your passion and how did you get involved in Parkinson's awareness and hope for a cure?

I first became involved with Parkinson's advocacy by writing letters to my state lawmakers, requesting more awareness/acknowledgment of Parkinson's as well as for a Parkinson's state registry. I have testified at the local level and helped obtain proclamations regarding Parkinson's Awareness Month in several cities in my state. I was recently invited to testify to my district's members of Congress, urging them to cosign the National Plan to End Parkinson's Act.

Many people tell me they were worried or scared to share their stories, but because I have, they now feel more comfortable sharing their experiences.

What type of goals do individuals with Parkinson’s have when viewing your messages?

I have had a lot of messages from people who said my videos have inspired them. Some say they relate to them and thank me for putting my family out there for the world to see. It makes you vulnerable, but my family has been very supportive.

I have had individuals say they were not as aware of all the symptoms of Parkinson’s, but they learned about them from seeing my videos. I asked them to send letters to their Congressional representative to help fund foundations like the Michael J. Fox Foundation for support.

It is amazing to come together with others to share community and ideas, and it makes you feel like you are not alone. Doing the love letter videos makes me feel less powerless living with Parkinson’s. It empowers me and lets me feel a little in control.

What effect can it have on an individual with Parkinson’s?

Since launching YOPD Love Letters on Instagram, I have been able to reach two audiences: people who don’t know much about Parkinson’s and are hopefully being educated by my posts (and links to informational websites), and people living with YOPD who are looking for community. It is so important for people with YOPD to find each other, because our experience with the disease is unique.

We are in the prime of our lives, raising young children, and in the middle of our careers. We are balancing it all while also needing to make time for medication management, high intensity exercise, and multiple medical appointments. We are volunteering for field trips while managing chronic pain and presenting at work meetings while trying to manage our visible motor symptoms. We are running around all day, without time for naps that we desperately need. Our symptoms can change day to day, but the rest of our lives don’t slow down for us. Having a community of people who can relate to each other is vital.

What would you like to see as a future goal for your programs?

My goal is to help speed a cure. To that end, my current goal is to encourage as many people as possible to contact their lawmakers and urge them to support the National Plan to End Parkinson's Act.

What events do you participate in?

I'm involved in advocacy work and attend my local YOPD support group, hosted by the Brian Grant Foundation.

How does this also assist the caregivers?

I include posts about caregivers because they are the unsung heroes of families living with YOPD. They too are in the middle of careers, raising children, and are suddenly thrust into the role of caregiver on top of everything else. Because caregivers tend not to ask for help, I provide links to resources for caregivers (as well as for the people who love them and want to help).

How can someone get in touch? What is your website?

@yopd.love.letters on Instagram and Facebook.
Instagram at
https://instagram.com/yopd.love.letters?igshid=OGQ5ZDc2ODk2ZA==

If you had one final statement or quote you could leave for the Parkinson's community, what would it be?

If you have been considering becoming an advocate, this is your sign to take the leap. The best way to get the attention of lawmakers is to raise our voices. Telling your story (via letter, email, or direct testimony) as a constituent is very powerful. Your personal story about living with YOPD could be the catalyst to your lawmaker acting and passing bills that will help to speed up a cure.

Jamie Bryson, Parkinson’s Fight Club

Jamie Bryson’s Biography

I’m the father of three awesome boys, ages 5, 10 and 13. I’m the husband to my beautiful bride. I work full time, self-employed, in the real estate industry. I’m a PhD dropout, and I have two Master’s degrees which are not relevant to my line of work. And I have the student loans to prove it! I am an endurance athlete; I have competed in triathlons, including two full Ironmans and a bunch of 70.3s. The bike is my happy place, as I like to say, and lately I have been focusing on mountain biking and gravel biking.

Please tell me a little about your background and what got you involved with awareness.

I was diagnosed with YOPD in 2021 just before my 40th birthday. I got involved in awareness because I am a fighter and I wanted to help and inspire others to fight.

Fight Club is a community and a movement of people who choose to be resilient in the face of difficult circumstances. We focus on improving our mindset, improving our lifestyle, and always trying to be the best version of ourselves. We don't accept the status quo. We believe in progress. We fight, knowing we won't win every round, but we will keep getting back up when we get knocked down. We don't have a white towel to throw in. What we have is determination, perseverance, grit, and a refusal to give in to the disease.

Can you tell me more about your advocacy?

My podcast is called The Parkinson's Fight Club. I started it along with a Facebook group to inspire others with Parkinson's to fight the disease and not give up.

What is your passion and how did you get involved in Parkinson's awareness and hope for a cure?

I just started posting on social media and then started my podcast. What really motivated me to do it was that I felt like there were not really many groups or podcasts that were about fighting the disease. A lot of the groups are very sad and depressing. There are some great podcasts out there, but they are mostly informational and talk about living with the disease.

My approach is a bit different. I would describe this as the difference between playing offense and playing defense.

What type of goals do individuals with Parkinson’s have when working with you?

If I can help just one person with their mindset and inspire them to fight instead of being a victim, then I consider my efforts to be worth it. Of course, I hope I can influence and inspire many more than that. But you can’t fight this disease from the sidelines.

What type of training and how long are the programs?

I'm still in the beginning of what The Fight Club could become someday. I would love to have programs available online for group exercise, individual coaching, and training on things like nutrition and self-advocacy.

What effect can it have on an individual with Parkinson's?

Really what I want to do is equip people to fight. That starts with knowledge, and then a daily effort to manage your mindset. I want to give people hope and then give them the tools to turn that hope into belief.

What would you like to see as a future goal for your programs?

I'm still dreaming about this one!

How can someone get in touch? What is your website?

As of right now, would love for people to just subscribe to the podcast and/or my YouTube channel. In the future there may be a nonprofit and other resources.

If you had one final statement or quote you could leave for the Parkinson's community, what would it be?

Keep fighting!

Dianne Bramble, Paintings for Parkinson’s

Diana Bramble’s Biography

I was born in Kitchener, Ontario, Canada, in 1968. I have one younger sister. My father was a psychologist, who died in 2021. My mother is still alive and is a retired nurse. She is 85. I moved to Ottawa, Ontario, Canada, in 1992 with my then boyfriend who is now my husband, Tim Bramble. We have been married for 27 years and have two daughters, ages 21 and 19. We have a dog and a horse. Our lives are pretty normal.

Please tell me a little about your background and what got you involved with awareness.

My background is in nursing. I have been a nurse since 2000, although I no longer practice. I come from a family that is very politically active, and from an early age, I was taught to speak out if I thought something was wrong and needed correcting. It just came naturally to me to start advocating for people with Parkinson’s. I guess it’s in my DNA.

Can you tell me more about your advocacy?

My advocacy kind of changes as I see the need. I have talked to my local political representatives—municipally, provincially, and federally. I have advocated for better care, more money for research, and just for more awareness of the disease.

What is your passion and how did you get involved in Parkinson's awareness and hope for a cure?

I have several passions. I love riding horses, painting, writing, talking to people about Parkinson's, and generally enjoying life. I got involved in Parkinson's awareness pretty much as soon as I was diagnosed in September of 2013. I needed to find out more about the disease and as I did, I realized that I needed to teach others what I had learned. I know there will be a cure, and I will be around for it!

What type of goals do individuals with Parkinson's have when working with you?

I think the people around me have similar goals of spreading awareness and advocating for more money for research.

What effect can it have on an individual with Parkinson's?

The effect I can have has been to give people hope. I feel hopeless sometimes, but mostly I am so focused on my goal of finding a cure, it doesn't last long.

What would you like to see as a future goal for your advocacy?

As for a future for my advocacy, I would like to continue working with government officials and researchers.

What events do you participate in?

I participate in the Parkinson SuperWalk every year. This year will be my 10th year. I am going to the World Parkinson Congress this year. It will be my first one.

How does this also assist the caregivers?

I like to think that I give caregivers hope as well as patients.

How can someone get in touch? What is your website?

People can get in touch with me at
dianne.bramble@gmail.com,
or https://www.facebook.com/BrambleDianne
or https://www.facebook.com/theaccidentalsuperhero/.

If you had one final statement or quote you could leave for the Parkinson's community, what would it be?

Don't ever give up. There is always hope. Find someone to talk to if you are feeling down.

Angie Gwinn on Advocacy

Angie Gwinn's Biography

I am married with four grown children (two are bonus children) and two bonus grandsons, whom I absolutely cherish. I have one cat I picked and two that picked me, as well as a dog that was left to my husband when his brother passed. I am a special educator and have been for 18 years. Fifteen of those years were in middle school, which lets you know that I don't scare easily.

I grew up in Florida and attended college (the first time) at Florida State University and received my first job in Miami. As my family migrated back to North Carolina, I decided to join them in 1990. I raised my children here, divorced here, remarried here, and went back to school for my teaching license and eventually went back here for my Master's in reading education he.

Please tell me a little about your background and what got you involved with awareness.

I was diagnosed on January 18, 2022. This was after a year of looking into why my hand was stiff and unresponsive to my brain's commands as well as not being able to lift objects that usually were picked up with ease.

I tried to find a support group in my area. Soon it became apparent that support groups are for nonworking people with PD. I work 7am to 4pm as an elementary special educator. None of the meeting times fit my schedule.

This is when I moved to social media. I created an Instagram account called, "angie.a.gwinn_shake.rattle.rol." This name describes my future. Right now, I shake, as the disease progresses, I will rattle, and eventually, I will be rolling in a wheelchair. Yes, a little dark humor.

The first people I followed were @littlelauraliving, @markinthepark, and @ladyduffgordon. Through watching these people advocate for themselves and others, I grew to understand that PD is not a well understood disease. Its effects are different in each person, and it does not discriminate. Through people I met on Instagram, I found out about two Facebook groups called "Twitchywoman" and "STRONGHER: Women Fighting Parkinson's." These two groups are full of women trying to navigate a male-dominated disease. I tried to start my own Facebook group before I found these, and it was a resounding flop! Obviously, the women who started their groups know how to do it. I have found answers to questions, laughed, congratulated, and commiserated in these online support groups.

Can you tell me more about your advocacy?

The advocacy I am involved in is very small scale. I decided from the beginning of my diagnosis in January of 2022 that I would not be silent. I tell people. I am not ashamed of this diagnosis; it is what it is. I mainly use humor so as not to bring discomfort to the people I tell. For example, the other morning I did not exercise before work so my tremors were visible. I told my coworkers that if they needed any help shaking something, I was available.

I love the hashtag movement #parkinsonslookslikeme. I want to scream that phrase from the hilltops! I am only one person, but I can be loud. If you have known me for any length of time, you would know that I am very self-conscious and introverted. That is a whole other story, and I probably need therapy. So, for me to start talking about PD the passion must be there. I have a passion to let others know that PD can affect anyone, and that resources and support are all around us even if you are fortunate enough to continue working.

What is your passion and how did you get involved in Parkinson's awareness and hope for a cure?

My passion is teaching students to read. I am a licensed reading specialist and I work with students who are 2 or more years behind their peers of the same age. PD is not a passion; it has become my new normal. With that said, I do advocate and try to get involved in studies or spread the word through social media. I like the saying, "You may not be the one who affects millions, but you could be the one that impacts one that affects the million."

The first study I became involved in was the Michael J. Fox Parkinson's Progression Markers Initiative (PPMI) study. I learned about it through my long-time friend, Anne, whose father died from complications of PD. I am also involved in a women's PPMI study.

Both of these are questionnaire studies that follow progression. My children are also involved in the PPMI study.

I recently signed up for a study that involves genetic testing. I should receive my kit soon. I am interested to see if I have a genetic reason for PD or if it is environmental. I raised my children in a rural area surrounded by farmland. I now know that the farmers used pesticides that have a known link to PD through ground and air spraying. I lived in a one-street neighborhood of approximately 35 houses. Within 16 years of my living there, one woman died of a brain tumor, one of a neurological disease, and I have PD. These are just the ones I know about. I am truly concerned for my children. I left the city to raise my children in what I thought was a cleaner environment and may have unwittingly had them exposed to neurotoxins.

It has occurred to me that my passion is stopping the indiscriminate use of pesticides that are known to cause cancers and neurological diseases. As I have started reading and noticing, chemicals that are harmful to humans are used in all areas of production, including our food supply. But how? Where do I start?

What type of goals do individuals with Parkinson’s have when working with you?

I am only one person, but my goal is to let people know that Parkinson’s looks like me. As I said before, it is an equal opportunity disease that affects people differently and is increasing in prevalence.

What would you like to see as a future goal for your programs?

I was going to try to start a PD support group in my town for women who work. Unfortunately, I have not started that process beyond talking to Lauren Simmons from PD Buzz. She gave me great insight into how to start a group. I have not followed through because, as I said before, I am an introvert and self-conscious. I need to get over that.

What events do you participate in?

I have participated in two events so far. One was in April 2021 called "Move-it" Day for Parkinson's of the Carolinas. My friend and I raised over $500 for that event. I also participated in an adapted climbing event with Catalyst Sports in Asheville, North Carolina. That is where I met @littlelauraliving in person! She also introduced me to other women with Parkinson's. I talk to these women to this day for support and to encourage each other.

How does this also assist the caregivers?

The Catalyst Sports Adaptive climbing event was great for my husband. He was able to meet other husbands who understood the disease through caring for their wives. I would love to find a support group for him. He keeps a lot bottled up.

How can someone get in touch? What is your website?

The best way to contact me is through Instagram at
angie.a.gwinn_shake.rattle.rol
or my personal email
keithangie0222@gmail.com

If you had one final statement or quote you could leave for the Parkinson's community, what would it be?

Attitude is everything! Push yourself to exercise, surround yourself with positive people, and advocate for yourself and others with Parkinson's disease. Don't be silent, don't be embarrassed. We must join together as one voice so that Parkinson’s disease can become a footnote in history.

Thomas Cosentino, Ambassador, Davis Phinney Foundation

Thomas Cosentino's Biography

In June 2015 my younger brother was diagnosed with lung cancer. Unfortunately, it was bad, and it had spread to other parts of his body. I was fortunate enough to be there when he finally passed. Some point that day I started having tremors in my left arm. After a week or so, when the tremors weren't stopping, I spoke with my primary care physician, who thought that I may have Parkinson's. He suggested that I go to the local hospital's emergency room because they can run tests that he wasn't able to do.

Initially, I was diagnosed with a pinched nerve and essential tremor. After a couple of months with the physical therapist, we both concluded that this was not a pinched nerve. I went to see a neurologist, who diagnosed me with Parkinson's.

I was able to work the first 4 years of my diagnosis. The stress of my job got to the point that my Parkinson's was out of control, and I had to step down from my position and ultimately went on long-term disability.

Today I am an ambassador with the Davis Phinney foundation. I have taken the last 8 years of my life to turn them into something meaningful by helping others.

The Davis Phinney Foundation

The Foundation is a 501(c)(3) nonprofit organization, designated by the Internal Revenue

Code. *We have reached hundreds of thousands of people with practical tools and resources focused on helping people with Parkinson's improve their quality of life. Until there is a cure for Parkinson's, we'll continue to lead the way in quality-of-life resources by bringing innovative programs and research to life. We provide information, inspiration, and tools to help people with Parkinson's live well today*.

See more @ https://davisphinneyfoundation.org/faq/

Please tell me a little about your background and what got you involved with awareness.

I was diagnosed with Parkinson's in 2015. I continued to work at that time until 2019, when I essentially lost my job because of Parkinson's. At that point I started getting more involved with some support groups. As I got to know these individuals, I came to have a great amount of respect for them, how they dealt with Parkinson's, and how they looked at the world. I felt the need to do something.

Can you tell me more about your advocacy?

As an Ambassador with the Davis Phinney Foundation, I try to help educate newly diagnosed Parkinson patients. I'm also part of three support groups, and I see myself as an influencer for those who need more information on Parkinson’s. I have also done some work with the Michael J. Fox foundation discussing these issues with our US senators and Congress people.

What is your passion and how did you get involved in Parkinson's awareness and hope for a cure?

I have not done much with the hope for a cure. I try to help work in the present.

What type of goals do individuals with Parkinson's have when working with you?

The goal varies from person to person. I try to teach them when I call the poor pillars. Find a great mission-driven organization, support group, exercise, and diet.

What type of training and how long are the programs offered by the Davis Phinney Foundation?

See https://davisphinneyfoundation.org/events/

Community Events

Our community events partner with members of our Healthy Parkinson's Communities™ network and are aimed at raising awareness, improving Parkinson's health literacy, showcasing Parkinson's resources, increasing volunteerism, and fostering connection.

Fundraising Events

Have fun and fundraise at one of these upcoming events with Team DPF, our grassroots fundraising community that raises money to help people with Parkinson's live well today.

What effect can it have on an individual with Parkinson's?

I let them know that there are people out there just like you and that you are not Parkinson's. You just happen to be a person with Parkinson's. Also, I try to give them a broad view of what's happening so they can fit better and deal with the disease.

What would you like to see as a future goal for your advocacy?

I am working on some PowerPoint slides which offer simple explanations of how to live better with Parkinson's.

What events do you participate in?

I try to attend local events and participate in three support groups.

How does this also assist the caregivers?

If you can teach someone with Parkinson's how to live a better life, that takes a tremendous amount of pressure off the caregiver. I think we tend to forget the role of the caregiver with Parkinson's.

How can someone get in touch? What is your website?

thomas.cosentino@gmail.com
https://davisphinneyfoundation.org/
1-866-358-0285
contact@dpf.org

If you had one final statement or quote you could leave for the Parkinson's community, what would it be?

I'm not Parkinson's. This is a hard road we travel, so we must find ways of living the best life we can today. At the end of the day don't let Parkinson's dictate who you are.

Anthony Rose, Puckfarkinson’s

Anthony Rose’s Biography

I’m 54 years old and was diagnosed with Parkinson’s in 2019. My 3 children are 16, 18 and 22 and understand why some things take me longer now. I’m still working as a director in an accounting firm, although I work from home occasionally to reduce the stress.

I wanted to blog about my experience to raise awareness. I originally wanted to call it another name, but my Mum objected so “Puckfarkinsons” it became. The smiley face came about because I put my brain DaTscan on Facebook and one of my friends added a smile to it. Without my friends, I don’t think I would be in the place I am today.

Please tell me a little about your background and what got you involved with awareness.

I’m a father of three kids and our 25th wedding anniversary is next year. I’m an accountant (and lucky to have understanding coworkers). I was diagnosed with Parkinson’s disease on 10 January 2019 when I was 49 years old. After coming to terms with my diagnosis, I decided to do several things:

- blog about my “journey” with the disease,
- participate in as many research programs as possible
- fundraise for Parkinson’s charities (especially those research-oriented).

Can you tell me more about your blog?

I have a blog about my experience with the disease.

What is your passion and how did you get involved in Parkinson’s awareness and hope for a cure?

I like to run, and it was while I was running that Parkinson’s first appeared. It took nearly three frustrating years until I was diagnosed and the mystery afflicting my legs was solved. Just after I was diagnosed, there was a program on the BBC about a trial of glial cell line-derived neurotrophic factor (GDNF), a growth factor used in studies of PD. One of the participants was Tom Isaacs, who founded the Cure Parkinson’s charity in the UK. He inspired me to do as much as I can to raise awareness and fundraise for a cure. I know that the speed of medical research will mean a cure will not be around in time for me, but I want to make sure that future generations don’t suffer from this disease.

What type of goals do individuals with Parkinson’s have when reading your blog?

I’ll have to ask, but I hope that they want to understand about the disease and hopefully help to spread awareness.

What effect can reading your blog have on an individual with Parkinson's?

I have been told that it helped fellow Parkinson's patients understand areas of the disease that they didn't know about (diet, symptoms, etc.) and inspired them to do more for fundraising for research.

What would you like to see as a future goal for your Puck Farkinson's?

A resource to help people with Parkinson's understand their journey and hopefully raise a smile along the way. It would be a bonus if the fundraising side could raise enough to fund (or seriously contribute to) a specific research project.

What events do you participate in?

I run trail ultramarathons. This year I'm hoping to complete four 50-mile events around the south of the UK, and I've just signed up for a 200 mile race in December, which should be interesting!

Can Puck Farkinson's also assist caregivers in anyway?

I'm aware that my posts can exhibit the "traditional" British inhibition. Hopefully I'll add more emotional information so that carers will understand what someone with Parkinson's is going through.

How can someone get in touch? What is your website?

I'm on twitter, Instagram (and now Threads as that seems to be a thing), and my blog page is www.puckfarkinsons.uk

If you had one final statement or quote you could leave for the Parkinson's community, what would it be?

It's something that I kept telling myself after my Mum died from cancer during the pandemic: "Keep looking up."

Nikos Koukoulakis, Parky Lifting on Weight Training for PD

Nikos Koukoulakis's Biography

- PD patient, athlete, coach at Hellas Team Parkinson Powerlifting, Parky Lifting.
- Studied at Athens Medical School.
- Studied at Athens University of Physical Education and Sports Science.
- Went to First Lyceum Kessariani.
- Lives in Kaisarianí, Attiki, Greece.

Please tell me a little about your background and what got you involved with awareness.

I still remember the words of my hematologist in 1999 after aggressive chemotherapy about end-stage blood cancer, with metastases to the colon and bone marrow: “Exercise saved your life.” This phrase, although I did not understand it, stuck in my mind.

After the chemotherapy treatments, some strange symptoms began that I could not interpret. They had to do with balance and difficulty writing. As a photographer I found it difficult to activate the camera plot. From a good photographer, I had evolved into a useless photographer. Then comes the diagnosis of Parkinson's disease and I lose my job. So, I turned to my young dream of studying gymnastics.

What is your passion and how did you get involved in Parkinson's awareness and hope for a cure?

I've always worked out, mainly with weights and powerlifting. I prepared my first paper with kinetic analysis of standing up for people with Parkinson's disease. In my Master's degree at the Medical School of Athens, where I won a scholarship in molecular and applied physiology with specialization in exercise therapy, I worked on the effect of exercise on Parkinson's disease. At the same time, I am a coach of the Greek Special Olympics Powerlifting team. I have taken part in triathlons, cycling and running races, and powerlifting, until I meet the freeze of gait. A lot changed after that.

What type of goals do individuals with Parkinson's have when working with you?

During the pandemic I didn't have access to gyms, and absolute disaster came. The disease progressed rapidly, to the point where I could not walk outside the house. I set up my own gym at home since I couldn't go out. I inform friends with Parkinson's, and we work out together. Slowly the difficult symptoms begin to subside, not the disease; the disease progresses.

There I understand the importance of the muscular system in disease. Due to the difficulty of movements and stiffness, I understand that I need more strength to walk, which strength can only be gained by resistance training.

What effect can it have on an individual with Parkinson's?

Weight training may reduce the symptoms of freeze of gait in Parkinson's patients.

See Parkinson's disease with freeze of gait Nikolaos Koukoulakis https://www.youtube.com/watch?v=2IkTJ932cNU

What would you like to see as a future goal for your weight training?

I received a message from my friend and Dutchman Ruud Overes that he is preparing for the Parkinson Games to be held in Eindhoven, the Netherlands, and he wants me to carry the flame of the games into the stadium as a torchbearer. I suggest that he put powerlifting in the program of the races.

I help with the World Federation, world powerlifting, and the help of Andreas Koletti (who is also a coach in the Special Olympics), Parkinson's category, where I do the editing of the regulations based on the needs of athletes with Parkinson's. I managed to create a small but strong group of Parkinson's patients together with my sister, who also has this disease, and we participate in powerlifting competitions.

What events do you participate in?

Triathlons, weight training.

In November 2024, the World Table Tennis Games Parkinson's will take place on the island of Crete in collaboration with the Hellenic Table Tennis Federation and the World Tennis Federation. I undertook to create the team and the Greek Federation to coach it. So, we are training for the championship in Crete.

How can someone get in touch? What is your website?

YouTube

https://www.youtube.com/channel/
UCiRiSwUzWX_zieNb-IvVwrA

If you had one final statement or quote you could leave for the Parkinson’s community, what would it be?

Exercise is not an option for people with Parkinson’s. It is mandatory, because it is the only medicine without side effects that can reverse the symptoms of the disease.

Sharon Krischer, Sunday Mornings with Twitchy Woman and Parkinson's Foundation, Ambassador

Sharon Krischer's Biography

Sharon Krischer was diagnosed with Parkinson's disease in January 2009. About 6 years ago, Sharon started writing a blog called "Twitchy Woman, My Adventures with Parkinson's disease" to fill a need for information about living with Parkinson's disease from the patient's point of view for people who were newly diagnosed. Her goal is to present living well with PD in a positive, sometimes humorous way.

Sharon lives in Beverly Hills, California, with her husband, Joel. They have three daughters and four fabulous grandchildren.

Please tell me a little about your background.

I grew up in the Midwest (St. Louis), went to the University of Illinois and University of Michigan. After my husband finished law school we moved to Los Angeles. I got my Master's degree in audiology and worked for several years as an audiologist. Eventually I stopped working and got involved in volunteering for several nonprofits, eventually becoming my synagogue president and a regional president for Hadassah. That is where I learned my leadership skills. When I was diagnosed with PD, I tried to ignore it and told very few people for about 5 years, and after that I could no longer hide it.

Can you tell me more about your organization?

I never set out to make Twitchy Woman and an organization, but the pandemic changed everything. I had been coordinating a loosely organized group for women with PD in Los Angeles for a couple of years (see next question for more on that). When the shutdown was announced, we immediately went on Zoom. Nine women attended the first meeting, about 30 came to the second, and it grew very quickly to include women from all over the world. We added chat groups, a mentoring program, and a book group as the need arose. We are totally volunteer run.

What is your passion and how did you get involved in Parkinson's awareness and hope for a cure?

When I was diagnosed in 2009, there was almost nothing on the internet except for about two blogs, the Fox Foundation, and a few others. It took me 5 years to accept my diagnosis and get involved. The first event I went to was a Fox Foundation day-long expo. That gave me some hope. Being a person who jumps into something 100%, I didn't take long to get involved in the Parkinson's world.

About that time, friends started to call and ask me to speak to someone they knew who was just diagnosed. Meeting with those people over coffee was the first step. I started my blog three months later so that I would have something to send to the newly diagnosed. I never considered myself a writer, but the blog came easily and really changed how I looked at PD.

After I started my blog, I learned from one of the few other bloggers about a 3-day symposium called the Women and PD Initiative, sponsored by the Parkinson's disease Foundation (which later merged with the Parkinson's Foundation). I applied and was accepted along with 25 other women. We were charged with doing something with what we learned after we returned home. That is when I started what we called the "nonsupport support group." The women wanted to do things, not just whine, so we had yoga, boxing, and speakers on many different topics. Women from around Los Angeles found us, and some even came from an hour away just to be with other women with PD.

What type of goals do individuals with Parkinson's have when working with you?

I think most want a place to belong as a woman with PD. They want to feel that they are part of a special group that meets their needs.

What type of training and how long are the programs?

We meet on Sunday mornings, about twice a month for an hour. We also have a mentor program developed by our women, which does require some ongoing training for the mentors. We have two chat groups and recently started a book group. All have been started by women who expressed interest in these types of programs.

What effect can it have on an individual with Parkinson's?

Most importantly, the women learn that there are many other women with Parkinson's like them. That they are not alone. Many feel more comfortable with their diagnosis because of participating in our programs.

What would you like to see as a future goal for your programs?

I think the next step for twitchywoman is to officially become a nonprofit organization so that we can hire someone to coordinate everything. The women have so many wonderful ideas that we cannot implement at this time because we don't have the money or staff to run more programs for women.

What events do you participate in?

Sunday Mornings with Twitchy Woman and occasionally our singles chat group.

How does this also assist the caregivers?

Currently, we don't offer anything specific for caregivers because of lack of time and funding. That may change if we get nonprofit status.

How can someone get in touch? What is your website?

Email: twitchywoman18@gmail.com.
website: twitchywoman.com

If you had one final statement or quote you could leave for the Parkinson's community, what would it be?

Don't give up hope, stay active, exercise, and eat well so that you can live your best life possible with Parkinson's disease.

Sandy Ellis, InMotion Parkinson's Wellness Center

Sandy Ellis's Biography

I am a boxing and spinning coach at InMotion Parkinson's Wellness Center in Beachwood, Ohio. These classes are designed to allow people of all abilities to participate, have fun, and leave feeling better than when they came through the doors. I have been in the fitness industry for over 20 years, and I love what I do. I hold National Collegiate Athletic Association (NCCA) certifications from the American Council on Exercise and the American College of Sports Medicine plus certificates of completion in Parkinson's Specialty programs. I am blessed to be part of what I think is the best team of Parkinson's specialty coaches and volunteer coaches in Northeast Ohio. Teamwork truly makes the dream work!

Please tell me a little about your background.

My Dad had a genetic disease where his symptoms were like those of PD. I chose a career in the fitness industry because of growing up seeing his enthusiasm for staying active every day. In 2014, I noticed that he was having trouble with his balance and gait but when he rode his bike the symptoms lessened. He was on the bike patrol for his local bike trail and was able to ride the 20 miles each way with balance and ease. After a Google search, I found Dr. Jay Alberts had already done research on the correlation between bike riding and PD symptoms. Due to these findings, he started the Pedaling 4 Parkinson's (P4P) program. This caught my interest, and I knew right then that I wanted to work with individuals living with movement disorders, but I wasn't sure where to start. I had recently completed a course in adaptive yoga, and through that network I was connected to InMotion.

In March of 2015 I was invited to become a Mindful Movement Coach at the soon-to- open InMotion Parkinson's Wellness Center. I found my passion, and I could not wait to learn more of what I could do to make a difference in the lives of those living with Parkinson's. During 2015-2016 I traveled to Sarasota, Florida, to train with the P4P coaches at the Berlin YMCA. The YMCA is now Core SRQ and the classes are still active. I have great thanks to the many hours those coaches spent with me answering questions and allowing me to teach Setting Us Up for Success when we started InMotion spinning classes in September 2016.

My desire to learn didn't stop there, as I found my niche in teaching the classes requiring a little more cardio so in April 2016, I headed to the Rock Steady Boxing (RSB) headquarters in Indianapolis and completed RSB training camp to become an RSB Trained Boxing Coach.

Can you tell me more about your InMotion?

InMotion uses a community-based group approach to help people with Parkinson's feel better every day. Through evidence-based exercise, arts, support, and education programs, we help clients take control of their symptoms and learn to live positively and constructively with their disease. Our findings show that in aggregate, in the clinical course of regular participants in our programs, they often remain stable or improve, illustrating the power of a holistic community-based approach to wellness for people with Parkinson's and their families.

The agency consists of specialized trainers, staff, coaches, and volunteers, who help clients with PD and their care partners, at no cost.

As a nonprofit 501(c)(3) organization, and one that offers its services to clients at no charge, we rely on the generosity of individual donors, foundations, grant-making bodies, and corporate sponsors."

What is your passion and how did you get involved in Parkinson's awareness and hope for a cure?

My passion is fitness and making it accessible to everyone!

What type of goals do individuals with Parkinson's have when working with you?

Using a holistic approach to improve or reduce people's symptoms for a while along with improving strength, balance, and confidence.

What type of training and how long are the programs?

Exercise, arts and healing, speech and cognition and support groups. They range from 1 hour to 1.5 hours.

What effect can it have on an individual with Parkinson's?

Smiles, laughter, and new friends!

What would you like to see as a future goal for your programs?

InMotion Parkinson’s Wellness Centers in every major city and around the world.

What events do you participate in?

InMotion’s Pals InMotion.

Parkinson’s Foundation Moving Day.

How does InMotion also assist the caregivers?

Our caregivers are not only VIPs but so are our clients. They are welcome to participate in any of our programs with available spots! We don't charge anything for anyone to participate in our programs, including caregivers. Many choose to volunteer at our front desk or in our classes throughout the week. We also offer support groups for caregivers. While the person with Parkinson's is in a class, many caregivers gather in our café area and have become good friends. What I love about InMotion is that once you walk through the doors you are family.

How can someone get in touch? What is your website?

Visit our website www.beinmotion.org

If you had one final statement or quote you could leave for the Parkinson's community, what would it be?

I remember hearing this quote years ago and I think of it often, because our InMotion motto and signature for the classes is "Better Every Day"! "We may not have the power to make life fair, but we do have the power to make our lives better." Thanks for sharing and I love what I get to do every day at InMotion!

Carl Carter-Schwendler on Advocacy through TikTok

Carl Carter-Schwendler's Biography

My name is Carl Carter-Schwendler. I was diagnosed with Parkinson's disease a little over 10 years ago at the age of 43. I am retired now on long-term disability, but when I was working it was in the tech sector. I worked at Microsoft for 14 years and Amazon for another 9 years. I have been on the board of directors of the American Parkinson Disease Association, Northwest chapter, for the past 5 years, taking on the role of President for the last two.

Please tell me a little about your background.

When I was diagnosed, I wasn't very interested in finding a support group or participating in the Parkinson's community. Part of this was just my not being a very social person, but the larger part was that I was afraid of meeting people who were much further along with their disease progression than I was. After a couple of years, I joined a Parkinson's boxing class. Although the class had people in it who were much further along than I was, I discovered that this didn't bother me as much as I thought it would. I enjoyed the classes, and I liked talking with the other people with Parkinson's about treatment and symptoms after class.

Apart from a couple of television appearances as part of the boxing class, I still wasn't involved much with awareness. This changed when my neurologist suggested I join the American Parkinson's disease Associates (APDA) board. Since then, I have participated in many fundraising events and helped steer the programs we provide for the community.

What is your passion and how did you get involved in Parkinson's awareness and hope for a cure?

In early 2021 I had downloaded TikTok and was enjoying using the app. As Parkinson's awareness month came around, I decided to do a series on Parkinson's where I would post a video about a symptom or treatment once a day for the duration of the month. That was over 2 years ago, and I am still posting. I found that there were more people with Parkinson's on the app than I ever expected. It turns out that this is the kind of community that I was looking for. I still don't participate in any support groups, but between my boxing class, TikTok, and APDA events, I have found my community.

What would you like to see as a future goal for your advocacy?

My goals are modest. I'd like to expand the reach of my message, especially to disadvantaged communities. But I have no desire to go viral and become a large influencer. I want to stay true to my audience and provide fact-based slightly technical information about

Parkinson’s disease to the Parkinson’s community and those adjacent to the Parkinson’s community.

What events do you participate in?

I participate in almost all APDA Northwest events from our Optimism Walk, and our Magic of Hope gala to our conferences for helping the Parkinson’s community.

How does this also assist the caregivers?

Information about Parkinson’s is extremely valuable to caregivers. Much of the content provided by APDA is geared towards caregivers as well.

How can someone get in touch? What is your website?

People who want to follow me on TikTok can find me at
https://www.tiktok.com/@carlcs1.
To learn more about APDA they should visit
https://www.apdaparkinson.org/northwest/

If you had one final statement or quote you could leave for the Parkinson’s community, what would it be?

You are the same person you were before you were diagnosed.

Christopher Sutphin on Advocacy through TikTok

Christopher Sutphin's Biography

Amidst his slight southern drawl, you hear the commitment: to family, friendship, and advocating for Persons With Parkinson's (PWP). You also hear the intelligence—the fascination with the pathology and uniqueness of the disease he's fighting, and the wonder … at the randomness of it all in a vast universe. And yet here we all are together, friends that have become family, fighting this disease head on.

Chris has a website called Parkie.tv—t's still in its infancy, mostly due to the apathy common to PWP that he listed as one of his PD nemeses, but there's already some great content and more coming! In addition to the #parkinsonslookslikeme videos, he also has a newer series called "Real Talk," which is a live recorded roundtable discussion of issues related to living with Parkinson’s and geared towards things we don’t discuss in polite company.

Please tell me a little about your background and how you get involved in Parkinson’s awareness and hope for a cure?

Living in a rural area, I quickly realized the lack of local support groups. Granted this was near the start of the COVID pandemic, so what groups were local had pretty much stopped in-person meetings. So, I turned to the internet, starting with Facebook, and I found and joined several groups for Young Onset PD. The interaction was good but not what I was looking for. Next, I turned to TikTok (GASP!!!). And once I trained the algorithm to ignore the dancing teens, I found a community of Parkies that I now consider my family.

What type of goals do individuals with Parkinson’s have when viewing your social media advocacy?

I truly feel that the best thing we can do is share our stories, learn from each other, and do our best to pass that information to the next person and the medical profession.

What effect can it have on an individual with Parkinson’s?

Sharing our stories, so very important.

What would you like to see as a future goal for your advocacy?

To borrow from the MJF Foundation, I do not want to have to keep advocating. I want to put myself out of work.

What events do you participate in?

We (The Gray Strong Foundation) have a weekly online support call—amazing!! Very informal, and while we do try to stay on topic, after the first hour, all bets are off.

How does this also assist the caregivers?

Currently working to mirror the Parkie group to a weekly call for care partners: #parkinsonslookslikeus

How can someone get in touch? What is your website?

parkie.tv or graystrong.org

The best email for me is chris@parkie.tv

The Gray Strong Foundation

Moving Forward With Parkinson's

Gray Strong Foundation helps individuals #moveforwardwithparkinsons by providing medical needs and program resource support for Parkinson's patients and their families. Founded by local EMT Eric Aquino, Gray Strong Foundation offers much needed support and Parkinson's disease awareness to the Lehigh Valley and surrounding areas via fundraising initiatives, @tremblingEMT, social media tips and podcasts, medical resource information and exercise programs. Aquino is no stranger to generating successful nonprofit organizations as a former chapter president of a local Pink Heals chapter (easily recognized by their pink fire trucks) and current Michael J. Fox Foundation Ambassador.

For more info see https://www.graystrong.org/about-us

If you had one final statement or quote you could leave for the Parkinson's community, what would it be?

Don't Panic!! And that is not a typo, the semi-colon is there for a reason.

⁂

About the Author

Dr. George M. Ackerman is a college professor in criminal justice, business, and law. He received his Ph.D. from the School of Public Service Leadership, Capella University; J.D. from the Shepard Broad Law Center, Nova Southeastern University; and police certification from Miami-Dade College School of Justice. His current energy is focused on advocating for a cure for Parkinson's disease through a wide range of avenues and outreach activities.

Dr. Ackerman has participated in numerous charity events; has addressed community, governmental, and international groups; has interviewed people living with Parkinson's, researchers, and advocates; has given interviews; has written about his experiences and published books on PD; and has participated in and conducted seminars, with plans for continued and additional activities. He also leads support groups on caregiving and loss.

In memory of his mother, Sharon Riff Ackerman, Dr. Ackerman founded the website https://www.togetherforsharon.com/ to increase Parkinson's awareness and research toward a cure. His dedicated interest in and passion for this work continues undiminished.

Dr. Ackerman's other interests include running charity 5Ks, basketball, and family time with his wife and three wonderful children.

Author, ***A Son's Journey from Parkinson's Disease Caregiver to Advocate***. Order your copy @ https://www.togetherforsharon.

Acknowledgment

To my wife, Grether, and children, Brooke, Joshua and Eli.... You are my support and my everything in this world. You are always right by my side and drive me to accomplish things I never knew I could.

There is a fire burning in my heart and a passion to ensure my mother, Sharon, is never forgotten, and through advocacy and your sharing of these journeys, she will never be forgotten.

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words alone can ever express. I am forever grateful to each and everyone.

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Finally, thank you for your support, time, care, and love. Without your inspiration, this would not have come true, and you continue to amaze me, and your journey means the world to so many.

Together, our voices are so much stronger!

Sharon's son,

George

TO ALL WITH PARKINSON'S AND ALL ENGAGED IN THE FIGHT

We love you, we support you, and
you are never alone in this fight for a cure.

We will advocate together because
together our voices are so much stronger …
and I am just getting started!
—Sharon's son, George

TogetherForSharon®

In memory of my Mother, Sharon, to voice awareness
and hope for a Parkinson's cure.

Please visit and share:
https://www.togetherforsharon.com/