

INSIDE THE CIRCLE...

Lancaster County Parkinson's CIRCLE OF CARE Alliance

Issue #2



THE LANGUAGE OF PD: "OFF TIME"

"OFF" is a term doctors and researchers use frequently in PD's care and research. But people with PD may be less familiar with this term or what it means for them. "OFF" is time when PD symptoms—motor and sometimes non-motor—return, often because meds are not working optimally. Not everyone experiences "off time", but it is more common with taking levodopa for longer periods. Symptoms are as individual as a person's actual PD.

Treating "off time" begins with looking at how you actually take your medications. Taking levodopa doses later than scheduled or skipping them can lead to "off time". Combining levodopa with meals, especially high protein meals can also contribute to "off time". Or, it could also signal a flag to have your medications re-assessed by your neurologist.

The exciting news is that there are some meds currently available and some therapies under FDA review to offset "off time".

For more information, visit <https://www.michaeljfox.org/foundation/news-detail.php?ask-the-md-the-language-of-parkinsons-off-time> Then click on the October 19, 2018 article entitled "Ask the MD—The Language of PD: Off Time".

GREETINGS FROM THE BOARD:

With the holiday season upon us, we'd like to wish you all the blessings of good health, peace and happiness for you and your families. It is our mission that the information and resources we provide through the Lancaster County Parkinson's CIRCLE OF CARE Alliance will indeed equip you to enhance your quality of life and enjoyment of your everyday activities!!

OUR MISSION:

"To give those with Parkinson's Disorder and their caretakers hope in awareness, education, encouragement, and action to take control of and responsibility for their future."

OUR VISION:

"To improve the lives of those with Parkinson's Disorder and their caretakers."

PARKINSON'S CIRCLE OF CARE ALLIANCE

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2nd Annual CIRCLE OF CARE Parkinson's Symposium

A day of inspiration and information was held on Saturday, November 17th from 8-3 at the Emerald Foundation 2120 Oregon Pike Lancaster, PA. The 2nd Annual CIRCLE OF CARE Parkinson's Symposium featured speakers over a wide span of topics for PD families, as well as vendors providing information and products of interest to this community.

Keynote Speaker, Jimmy Choi, garnered national attention when he competed in the past two seasons of the American Ninja Warrior competition in Las Vegas, as an incredible role model for persons challenged with Parkinson's Disorder. He's currently training for the 2019 season! The crowd was enthralled with hearing Jimmy's story. What an amazing journey of courage and determination!!

For a wonderful clip about Jimmy's story, visit: <https://www.youtube.com/watch?feature=share&v=xgRDYZoUnac&app=desktop>



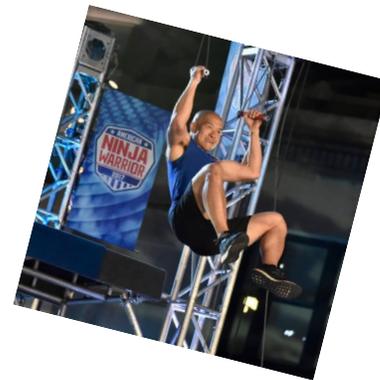
The CIRCLE OF CARE Board of Directors would like to thank the staff of the Emerald for the work they put into making the event and breakfast/lunch so successful. We'd also like to share our appreciation to all the volunteers and to the following pharmaceutical companies: Adamas, Abbvie, Acadia, Medtronic, Lundbeck, US Worldmeds. Finally, thanks to the local vendors: Senior Helpers, Insurance Insights, Rivera Physical Therapy, Shaklee, Saxton & Stump LLC, EHD Advisory Services, Neuro Scifit, (Rock Steady Boxing Lancaster), Young Living Essential Oils, VoxxLife, and Lancaster County Parkinson's Support Group.

Mark your calendar for next year's event:
November 9, 2019.





MEET OUR SPEAKERS:



JIMMY CHOI: AMERICAN NINJA WARRIOR

Now 42, Jimmy was diagnosed with young onset Parkinson's at 27. As time passed, he gained weight and walked with a cane. After a bad fall, he decided to change his lifestyle and take back some control of his life. He is now an athlete who has run, cycled and swum in countless races and endurance events to help speed a cure by raising more than \$250,000 to support Parkinson's research. Jimmy Choi is also a husband, father, public speaker and advocate. But many people know him as an athlete (Spartan races, marathons and such) and as a Ninja Warrior on the TV competition show. People of all abilities value his uplifting and inspirational message.

"I don't move like other runners, cyclists and I certainly don't move like other ninjas. Yet I try to find ways to defy the odds presented to me. When one road is blocked, change your course. You will find a way." (Jimmy Choi)

DR. STEPHEN GOLLOMP, MD; NEUROLOGIST-MOVEMENT DISORDER SPECIALIST

Dr. Gollomp is affiliated with multiple hospitals in SE PA. He has been in practice for over 20 years. Dr. Gollomp has a team approach to treatment of his patients. He spoke of the importance of the "therapeutic alliance of patient, physician and family".



SCOTT MITCHELL: ATTORNEY AT LAW

Attorney Mitchell discussed health and disability issues planning for the future. He counsels regarding the need to develop estate, long term and asset protection planning. He spoke to the audience on these topics specific to people with PD issues. Attorney Mitchell works for the Lancaster firm of Saxton and Stump.



JOYCE LIBBY, CFP, RICP: FINANCIAL ADVISOR and RETIREMENT SPECIALIST

Joyce has more than 25 years of experience in the financial services industry and possesses a wealth of experience in comprehensive financial planning for individual and business owners.

"Through in-depth discussion and analysis, we will work together to draft a plan designed to help you achieve your goals. During the planning process, we will coordinate with your other professionals to ensure the goals we discuss are properly addressed in your other legal documents." Ms. Libby discussed these financial considerations specific to the PD clientele.



INSIDE THE CIRCLE RESEARCH & RESOURCES

Michael J Fox Foundation

The Michael J. Fox Foundation is dedicated to finding a cure for Parkinson's Disease through an aggressively funded research agenda and to ensuring the development of improved therapies for those living with Parkinson's today. Visit their website at www.michaeljfox.org.



Davis Finney Foundation for PD

The Davis Phinney Foundation is a non-profit with a mission to help people with Parkinson's live well with the disease. It was founded in 2004 by Davis Phinney, the former professional road bicycle racer and Olympic medal winner. Phinney was diagnosed with young-onset Parkinson's disease in 2000 at the age of 40. Their website is www.davisphinneyfoundation.org.

Lancaster County CIRCLE OF CARE

The Circle of Care Alliance was created to improve lives in Lancaster County for people with Parkinson's Disorder and their caretakers. The non-profit strives to give those with PD and their caretakers hope in obtaining a quality of life through Awareness, Education, Encouragement and Action and taking control and responsibility for their future. Visit their site at www.parkinsonscca.org.



American PD Association

The American Parkinson Disease Association (APDA) is a large grassroots network dedicated to fighting Parkinson's Disease and works tirelessly to assist the more than 1 million Americans with Parkinson's Disease live life to the fullest in the face of this chronic, neurological disorder. The APDA website is www.apdaparkinsons.org.

WILLOW VALLEY COMMUNITIES HOST WELLNESS EXPO; GUEST SPEAKER, TIM HAGUE

On Tuesday, September 18th, Willow Valley Communities sponsored the 2018 Health & Fitness Expo for its residents and the community at large. It is estimated that about 800 participated in the event, which featured over 40 vendors who provided a wealth of wellness information for those in attendance.

The keynote speaker was Tim Hague, author of the book *PERSEVERANCE*, in which he shared his adventure with his son, as they won the first season of Canada's *AMAZING RACE*. Having been diagnosed with PD at age 46, Tim shared humor, suspense and inspiration as he shared tales of their competition. Also presenting that day was Martha Harris whose topic of interest was "Keeping Our Brains Healthy as We Age". Attendees seemed very well pleased with the day's events!

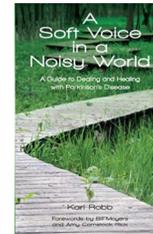
Contact the CIRCLE of CARE Alliance to purchase a copy of Tim's book in time for Christmas!!! What an amazingly inspirational Christmas gift!



(l-r--Bob McKane, Sue Drazba, Sue Ludwig, Connie McKane & Tim Hague)

Book Review Corner A SOFT VOICE IN A NOISY WORLD

by Karl Robb



Whether you are newly diagnosed or have had Parkinson's Disease for many years, or you are younger or older, the lessons that Karl Robb offers in this book will apply to your situation. A culmination of over twenty years of personal experience, Karl Robb provides an assortment of tips and suggestions that have made a difference in his life and benefited him in his personal struggle with PD. This guide shows how one man successfully navigated the medical gauntlet with the support of his wife and care partner, and found his answers, often in the unlikeliest of places. In this book you will learn how through maintaining a positive attitude and utilizing Reiki and other complementary therapies, Karl has kept his Parkinson's in check, slowed the disease's progression, and amazingly seen signs of improvement, even after over two decades of dealing with PD. This book is a compilation of hundreds of insights and practical tools intended to add inspiration and ease to your daily life, including suggestions and resources for bettering your patient-doctor experience, living a productive and happy life, staying fit and active, traveling, participating in support groups, being a PD advocate, improving your mind-body connection, and empowering yourself to heal. (Amazon Review)

Editorial Comment: I knew this was a special book when a local PD warrior, Jim Michael, commented that this author "gets it"!! He indicated the book was a "must" for all who face the challenges of PD.

QUOTE OF THE SEASON:

“It’s not always about hitting the buzzer when you want to be a winner.”

Jimmy Choi,
American Ninja

