

S P R I N G 2 0 1 9

# INSIDE THE CIRCLE...

Lancaster County Parkinson's CIRCLE OF CARE Alliance

Issue #3



## 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

57 Buttonwood Drive

Lititz PA 17543

717-568-8448

[parkinsonscca@gmail.com](mailto:parkinsonscca@gmail.com)

[parkinsonscca.org](http://parkinsonscca.org)

### BOARD OF DIRECTORS

Bob McKane—President

Connie McKane—Sec/Treasurer

Michelle Atwater

Rich Diem

Suzanne Drazba

Patricia Kline

Drew Nesbitt

## CIRCLE OF CARE Welcomes 2 New Board Members

Drew Nesbitt, Physical Therapist at HARTZ Physical Therapy in Lancaster, has become one of PCCA's newest board members. Drew is clinic director at the New Holland Avenue location. A Physical Therapist at Hartz since 2010, he has a passion for neurological and vestibular issues. Drew has also served on the board of Girls on the Run and continues his work on the Girls on the Run 5k race committee.

Drew received his Bachelor of Science from East Stroudsburg University in Biology and a Doctorate in Physical Therapy from Arcadia University. At East Stroudsburg, he was captain of the cross-country and track & field teams, and continues to run competitively. He is a member of the F&M Track Club.

Drew and his wife Amanda have two children: Dathan (6) and Dakota (3).



You can read Drew's article "How Can Movement Specialists Help Me Combat Changes in My PD Symptoms?" under our INSIDE THE CIRCLE RESEARCH & RESOURCES section on page 4.

Continue to page 2 to read about our second new board member, Rich Diem!





## Up-Coming Events:

Keep your eyes on our website  
(parkinsonscca.org ) for the following up-  
coming events:

Beer Dinner – August 5<sup>th</sup>  
2019 Symposium—November 9<sup>th</sup>

## CIRCLE OF CARE

### Welcomes 2 New Board Members (continued from page 1)

Rich Diem, a native to Staten Island New York, has lived in Central Pennsylvania for over 32 years. His career has been in finance, working as a Financial Analyst or as a Portfolio Manager for banks and his current Firm EHD Advisory in Lancaster.

Richard graduated with honors from the University of California at Santa Barbara in Business/Economics and obtained his MBA from the Smeal College of Business at the Pennsylvania State University. He is a Chartered Financial Analyst.

Richard lives with his family in Hershey Pennsylvania. His wife Wendy divides her time between home, and her Notary and her Stampin Up businesses. His son Patrick is a college bound senior at Hershey High School. His daughter is a freshman at the same school and spends all her free time at Hershey's One Broadway dance school.

Richard spends his free time working out or reading for work and pleasure. He has also been known to enjoy a spirited game of golf and a craft beer. Loyal to his roots, he follows all the New York professional sports teams.



### MEET OUR 2019 SYMPOSIUM KEYNOTE SPEAKER: BRET PARKER

Bret Parker is Co-Chair of the Patient Council of the Michael J. Fox Foundation for Parkinson's Research. He was diagnosed with PD in 2007 at age 38 but kept it relatively secret until he published a blog on the Forbes website in 2012. He now moderates a Facebook group for people living with young-onset PD.

Since 2012, he and his family and friends have raised over \$600,000 for Parkinson's research through activities such as runs, triathlons and skydiving. In early 2018, Bret completed the World Marathon Challenge completing 7 marathons on 7 continents in 7 days!!! He is Executive Director of the New York City Bar Association, where he coordinates and oversees the operation of this 24,000 member organization. Check out his full story at <https://www.washingtonpost.com/national/health-science/7-marathons-7-days-7-continents-and-one-man-with-parkinsons-can-he-make-it/2018/02/09/ef39ce80-0c14-11e8-8b0d->



## ASKING FOR & ACCEPTING HELP

Viki Kind

“In Your Corner”—Winter 2018



After a history of less-than-stellar experiences in caregiving, Viki Kind offers the following four steps to solicit, acquire and accept help in dealing with the challenges that PD can provide.

**STEP 1:** Explore what is keeping you from asking! Write down what goes through your head when someone says, “You should just ask for help!” Write down the kinds of resistance statements you use.

**STEP 2:** Take your list of resistance statements and now put a power statement beside each to help get past what has been keeping you from asking for help.

- They don’t know what I do. *I could teach them.*
- It’s just easier if I do it myself. *Only the first time!*
- Why should I have to ask? They should just know what to do. *Would I have known what to do before I became a caregiver? Why should they?*
- They don’t really want to help. *How do I know if I never ask?*

You will need to understand that your established way of doing things may not be the **ONLY** way and be open to others’ management ideas.

**STEP 3:** Make a list of all the things that would help you regarding practical, emotional, financial and informational support. Write a thorough list and carry it with you so that when someone asks, “What can I do to help?”, you can hand him or her the list and ask him or her what he or she would like to do. Your list can even be e-mailed to potential helpers.

Ask for specific things such as: Could you call Mom each week and provide some social interaction for her? Could you drive Dad to his therapy/exercise class and be his “buddy” once/twice a week? Could you call ME once a week to check in on MY need for support/comfort level? Could you hang out with my husband one afternoon so that I could go to lunch/shopping with some friends? Keep in mind that people can help from a distance, too. Things like setting up appointments, on-line grocery-ordering/delivery, paying bills, providing money for occasional respite care are just a few examples.

**STEP 4:** Ask a LOT of people! You may have to ask five or more people to find ONE who can take on a specific task. But it will be worth it!! Ask people for things that they can actually do! Different people have different abilities. Show them the list and let them choose what they would be comfortable doing. **There are more people who are willing to help in your circle of friends, family and community than you think!!** Other possible avenues to pursue are: churches/faith communities, local Agency on Aging, high school students, colleges/universities, veterans, and so on!

Viki contends that your work in getting help set up will be well worth the effort. The time spent up front will develop assistance for you on an on-going basis. Also, make sure you express your gratitude! Nothing goes further in making someone willing to help than knowing he/she is appreciated!

Finally, Viki suggests that if all else fails, don’t be afraid to tell family members “If you don’t have time to help, you need to pay someone to help me.” She concludes by encouraging her reading audience to have fun with the process and reminding them that “Your needs count, too!”.

# INSIDE THE CIRCLE RESEARCH & RESOURCES



## HOW CAN MOVEMENT SPECIALISTS HELP ME MANAGE MY PD SYMPTOMS?

.....  
 Drew Nesbitt, PT, DPT  
 Hartz Physical Therapy  
 CIRCLE OF CARE Alliance Board Member



*When should I be referred out by my movement specialist for physical therapy?*

Regular assessments by movement specialists, often at yearly intervals, help individuals maintain their fitness levels and stay as active as possible. When regression in these areas is identified, referral to a physical therapy practice is often recommended. Your physical therapist will become a partner with you and your family to help you manage your symptoms of PD. Your treatment program should be monitored and modified to help you maintain your optimal independence.

*What types of exercise should I perform to combat PD effects?*

Unfortunately, we have no specific magic bullets to combat PD, as no two diseases and personal environments are alike. Therefore, movement specialists who work with PD should have different types of assessments that lead to various exercises/treatments. Treatments should be multifactorial and address: body function/structural limitations, activity levels, participation rates in daily tasks, and mental abilities. Specifically, physical therapists can focus on such typical PD challenges as freezing of gait, fatigue, fall risk and the ability to perform multiple activities at the same time.

*How do physical therapists assess needs/progress in my movement areas?*

There are several tools that highly qualified movement specialists use to detect needs and monitor progress with individuals with PD challenges. Areas of review include: Body Structure & Function, Cognition, Activity/Participation Levels, Functional Gait and others as deemed appropriate by the clinician.

*What key points should I cover when discussing how to manage my PD symptoms with my movement specialists?*

Make sure the physical therapist to whom you are referred has experience effectively intervening with PD symptoms, as well as being capable of providing appropriate education re: symptoms/therapy/recovery. Be sure to establish a timeline for care, a clear understanding of activity/lifestyle expectations outside of therapy and a game plan for monitoring progress. Very importantly, insist on a partnering approach between movement specialist/neurologist, physical therapist and client/caregiver.





## April is... PARKINSON'S AWARENESS Month!!



\*\*\*\*\*

### What are Jimmy Choi & Tim Hague Doing this Spring?

Jimmy Choi was our keynote speaker at our 2018 CIRCLE OF CARE Symposium and Tim Hague, 2017. Both young men have PD! Jimmy competes on AMERICAN NINJA WARRIOR and Tim and his son won Canada's first season of THE AMAZING RACE: CANADA. What are they up to NOW??



**TIM HAGUE** is the founder of U-Turn

Parkinson's in Canada. U-Turn Parkinson's is unique in the Parkinson's community. They empower people living with Parkinson's in their pursuit of wellness. They are committed to supporting them through a holistic approach

because they see wellness as an active process through which people become aware of, and make choices toward a more successful existence. On February 17<sup>th</sup>, Tim stared down a daunting challenge---running in the Hypothermic Half in Winnipeg with his daughter, Jordana. On the start of this half marathon, the temperature registered -20 degrees! Brrrrrrr! They DID it!! Yay!!!

Don't miss the opportunity to read Tim's amazing book PERSEVERANCE!! Contact us if you'd like to purchase this book from CIRCLE OF CARE.

**JIMMY CHOI**, meanwhile, is training for the new season of AMERICAN NINJA WARRIOR, sponsored by the Michael J Fox Foundation. Jimmy's daughter Karina competes in the youth AMERICAN NINJA WARRIOR, too! On February 16-17, both Jimmy and Karina competed in the National Ninja League World Finals!!! Jimmy placed 12<sup>th</sup> in his age group and Karina crushed it and landed in 2<sup>nd</sup> place in her category!! Wow---Congrats, Dad and Daughter Ninja Warriors!!

Here is Jimmy's resume of athletic competitions since 2012:

5K's - Lost count	10K's - Lost count
Half Marathons – 101	Marathons – 15
Ultra Marathons – 1	Ultra Marathons – 1
50+ Mile Bike – Many	Grand Fondos – 6
American Ninja Warrior Seasons 9 and 10	
\$\$\$ Raised for Research - ~\$250K	



### Book Review Corner:

Anyone who is associated with PD knows of Michael J Fox! Following are a few glimpses into his three inspirational books! Take your pick! They are ALL wonderful...powerful...inspirational!!

#### LUCKY MAN (2003)

In September 1998, Michael J. Fox stunned the world by announcing he had been diagnosed with Parkinson's disease--a degenerative neurological condition. In fact, he had been secretly fighting it for seven years. The worldwide response was staggering.

Fortunately, he had accepted the diagnosis and by the time the public started grieving for him, he had stopped grieving for himself.

Now, with the same passion, humor, and energy that Fox has invested in his dozens of performances over the last 18 years, he tells the story of his life, his career, and his campaign to find a cure for Parkinson's.

#### ALWAYS LOOKING UP (2009)

At the turn from our bedroom into the hallway, there is an old full-length mirror in a wooden frame. I can't help but catch a glimpse of myself as I pass. Turning fully toward the glass, I consider what I see. This reflected version of myself, wet, shaking, rumpled, pinched, and slightly stooped, would be alarming were it not for the self-satisfied expression pasted across my face. I would ask the obvious question, "What are you smiling about?" but I already know the answer: "It just gets better from here."

#### A FUNNY THING HAPPENED ON THE WAY TO THE FUTURE (2010)

Michael draws on his own life experiences to make a case that real learning happens when "life goes skidding sideways." He writes of coming to Los Angeles from Canada at age eighteen and attempting to make his way as an actor. Fox offers up a comically skewed take on how, in his own way, he fulfilled the requirements of a college syllabus. He learned Economics as a starving artist; an unexpected turn as a neophyte activist schooled him in Political Science; and his approach to Comparative Literature involved stacking books up against their movie versions.



#### A FUNNY THING HAPPENED ON THE WAY TO THE FUTURE...



## QUOTE OF THE SEASON

Parkinson's is my toughest fight. No, it doesn't hurt. It's hard to explain. I'm being tested to see if I'll keep praying, to see if I'll keep my faith. All great people are tested by God.

MUHAMMAD ALI, *Esquire*,  
February 2012



INSIDE THE CIRCLE...ISSUE #3—SPRING 2019

