

# MICHIGAN MESSENGER

Exciting things are happening in Michigan!







### **UPCOMING EVENTS FALL 2017**

#### **SEPTEMBER**

- PD Self-Efficacy Program 13
- 16 Lansing Walk
- 22 Parkinson's Symposium in the Upper Penninsula
- 29 Parkinson's Symposium --Grand Challenges, **Grand Rapids**

#### **OCTOBER**

- TBD Living with Parkinson's Midland/Bay City
- 21 Kalamazoo Walk

Check website for additional educational programs and services. Ask to be placed on our email list to receive monthly eblasts



You Tube video on the MPF website: parkinsonsmi.org/ click on icon next to the search box

www.parkinsonsmi.org

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# Jeff Laethem, President of Ray Laethem Motor Village, elected to Chair the Michigan Parkinson Foundation



Dr. Edwin George & Jeff Laethem

In December 2016, Jeff Laethem was elected Chairman of the Michigan Parkinson Foundation. Jeff has served on the board since 2015 and assumed the role of Chairman in January, 2017, succeeding Dr. Edwin George who had served as Chairman since 2011. Dr. George will remain on the board and the Professional Advisory Board. Jeff will lead the Michigan Parkinson Foundation in its efforts to provide financial assistance for costly medications, adult respite care, legal guidance, patient and professional education programs, counseling, referrals for medical resources, 71 support groups throughout Michigan and grants

to fund research that can lead to improved clinical care. Jeff's goal as chair is to help ensure that the Foundation can support every Parkinson's patient in Michigan with compassionate, quality care.

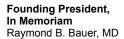


PETER A. LEWITT. MD

### A Golden Anniversary to Celebrate -Levodopa and Parkinson's disease

Over the past 50 years since it emerged for treating Parkinson's disease (PD), levodopa has been a mainstay therapy. Also known as L-DOPA, it is the active ingredient of Sinemet® and is available as a generic drug, mixed together with carbidopa. Levodopa continues to amaze patients and physicians alike with its remarkable ability for restoring functionality. The majority of patients experience improvements even from the first doses, and these benefits never are lost. Levodopa is one of the most

cost-effective medications ever developed. Even though other options are available for treating symptoms of PD, none has greater impact at improving quality of life for this disorder. Unlike many other medications, levodopa is nothing more than a simple amino acid, present in some foods and normally synthesized in the brain (although, in PD, not in sufficient quantity). The pharmacological concept behind levodopa involves replacing an important signaling chemical in the brain, dopamine, which is necessary for enabling normal movement and for preventing tremors and rigidity. Levodopa is not a cure and is far from perfect as a symptomatic treatment. Nevertheless, it is difficult today to imagine living with PD in the absence of this treatment option.



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Diane Kraft, Program Assistant Meri Sheen, Data Coordinator

MPF programs are supported by your gifts and by grants from the following sponsor: Community Health Charities The MPF is a volunteer dependent organization. Our volunteers are essential to our mission of providing support and education to people with Parkinsons, their families and the health care professionals who provide care for them. We have hundreds of volunteers working in the field, leading our support groups, teaching our programs, volunteering at the walk events or helping out in the office. There are too many to mention, but here are a few:



**Sean Frances, office volunteer**. "In 2014, I was diagnosed with Parkinson's Disease (PD) with Dementia. Prior to that, I knew very little about the disease, other than knowing that people who had PD experienced uncontrollable tremors. The only people I had read about having the disease were Muhammad Ali and Michael J. Fox. I had never met anyone with PD.

I had stopped working in order to be a caregiver to my elderly mother who had breast cancer. For a while I ignored the initial mild and varied symptoms I was experiencing, because my attentions were needed else-

where. However, my symptoms became more and more pronounced, to the point they no longer could be denied or rationalized. I sought out specialists who were able to determine that I had PD.

My mother has since died, and I now require my own caregiver to assist with medications, symptom management, memory/cognitive issues and transportation. Fortunately, I have a sister who has been willing and able to provide such support. Like many other PD patients, one of the more challenging symptoms I have had to overcome is depression. For a long time, I avoided leaving the house or making commitments. However, my doctor strongly recommended that I exercise, so I walk 2 miles every other day.

Eventually, my sister persuaded me to maintain a more positive attitude, and to feel more productive, by doing volunteer work. I spend one day each week at the Michigan Parkinson Foundation, providing office and clerical support. The office staff is small and there is always work to be done. They are always happy to see me and I think they have come to rely on me. It's good to be needed. I can honestly say that since I started volunteering, I feel better emotionally and am more willing to socialize with others.

Also, I am participating in a couple of clinical studies to develop more effective medications to treat the symptoms of PD, and to one day find a cure. This is something positive I can do

to help myself and others."



Matt and son, Rocco

Matt Dishman. Matt is one of those "super volunteers" that non-profits come to depend upon. Matt served as the chair of the St. Clair Shores walk for several years. Luckily he remained on the committee when we moved the walk to Birmingham and once again, his calm demeanor, 'take charge' attitude contributed greatly to the success of the day. Thank you Matt! You are a hero to the MPF!

Connie Spiteri, a longtime volunteer (with husband John at her side), has held numerous volunteer roles with MPF including Chairperson of the "I Gave My Sole for Parkinson's" Northville Walkathon; member of the Planning Committee for "A Night of a Thousand Stars" as well as obtaining Silent Auction Items for the event; and facilitator of the Howell Support Group. Connie never hesitates to offer her great organizational skills when needed at MPF offices to help out the staff.

#### PRICELESS!



Nadji Reynolds was a longtime volunteer each Friday at MPF Offices until she "retired" from MPF in August 2016. Nadji was multi-talented and could accomplish any task set before her. One of Nadji's main responsibilities was to keep a large quantity

of MPF's Information and Referral Packages ready to be mailed as people newly diagnosed with Parkinson's reached out to MPF. The staff at MPF misses Nadji greatly!!



We want to thank and acknowledge the following folks for their dedication and many years of service to the St. Clair Shores Walk

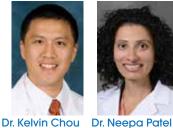








Karla and Larry Anderson





Kelvin Chou, MD, co-director STIM,

University of Michigan and Neepa Patel, MD from Henry Ford Health System Parkinson's Disease and Movement Disorders Program. Both physicians serve on the MPF Professional Advisory Board and are frequent speakers who donate their time to teach our various Parkinson's education programs throughout the year. They are popular with our constituents and are in much demand. We are grateful to all the physicians and health care professionals who serve on our professional advisory board (PAB) and donate their

time and talent to our programs.



Steve & Rose Femminineo – Steve was diagnosed with PD eight years ago. Steve shares his optimistic and positive attitude with others. He teaches the Orientation to Parkinson's programs for the newly diagnosed and the PD Self Efficacy Program, a nine session program which meets monthly. Steve is generous with his time and knowledge, often reaching out to newly diagnosed patients to help them navigate through the daily challenges of living with PD. Steve and his wife Rose are an amazing team and the PD community is fortunate to have them in their corner.

WHAT IS PD SELF? A national pilot program of the Parkinson's Foundation that provides people with Parkinson's an in-depth understanding of the disease and the self-efficacy tools to manage it with confidence.

# Are You Recently Diagnosed with

Join an innovative program designed to help you manage PD and improve quality of life.

WHO IS ELIGIBLE? People with Parkinson's

and their care partners within three years of diagnosis who can commit to a nine-session program.

WHAT IS SELF-EFFICACY? The ability to have influence over the conditions that affect our lives. A scientifically-based approach that is effective in helping people with Parkinson's to develop the motivation and skills to manage PD.

WHO DELIVERS THE PROGRAM? A health care professional and a person with Parkinson's both trained in the application of self-efficacy for Parkinson's.

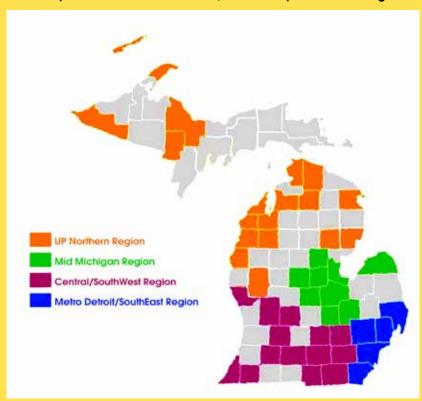
HOW OFTEN DOES IT MEET? The 2nd Wednesday of each month, from 1 PM to 3:30 PM, starting on September 13th. The program lasts nine months. There is no cost to attend. Space is limited.

To learn more about PD SELF, contact the Michigan Parkinson Foundation (MPF) at 248-433-1011. PD SELF is being conducted in collaboration with National Parkinson Foundation and the Michigan Parkinson Foundation.

The program takes place at the MPF office, located at 30400 Telegraph, Bingham Farms, MI 48025

## Find out what's happening in your area

Map of location of Michigan Parkinson Foundation-affiliated Support Groups. For detailed information, view www.parkinsonsmi.org



Alpena Ann Arbor

Antrim County (Bellaire)
Barry County (Hastings)

**Battle Creek** 

**Battle Creek Young Onset** 

Bay County
Bay County Mid
Michigan Young Onset
Berrien County

(St. Joseph)
Cadillac

Calumet

Cass County/Cassopolis

Cheboygan

Dearborn Detroit

Dickinson County – Parkinson's Society Farmington Hills

Flint Daytime Flint Evening Frankenmuth

Frankfort

Gaylord (OCCOA-Gaylord)

Gladwin Grand Rapids

Grand Rapids - Hauenstein Center

Grand Traverse - Evening Group

**Gratiot County** 

Hillsdale

Howell

Ionia

losco (East Tawas)

Ironwood

Jackson

Kalamazoo

Kalamazoo Care Partners

Lansing Caregivers' / Dialog Groups

Lansing/East Lansing

Leelanau

**Lenawee County (Adrian)** 

Livonia (Western Wayne)

Macomb, (Beaumont Macomb Center)

Manistee

Mason County (Scottville)

Midland Monroe

MovingUPTogether (Young Onset)

Mt. Pleasant (CMU)

Muskegon: Parkinson's Power

**Muskegon Caregivers** 

Negaunee/Marquette County

Newago County Novi/Fox Run

Owosso

Parkinson Network North

(Traverse City) Petoskey

Port Huron

Rochester

Rochester Care Partners
Royal Oak/South Oakland
Thumb Area (Bad Axe)

Tri-City/Saginaw

Warren

wanen

West Bloomfield West Branch

Young Onset of Southeast Michigan

For Specific Information About Parkinson
Support Groups, View Our Website:
www.parkinsonsmi.org

If you do not have access to a computer,
please contact us at 248-433-1011

#### NO LONGER MEETING

**ESCANABA** – Thank you to **Michael & Diane Oxford**, who started the group back in 2009 and additional Thanks to Fred & Ellen Chenail, who co-facilitated the group since 2012.



Mary Griffore, Mary Sue Lanigan, Laura Zeitlin, Linda Grap, Kate Hodgkins



Colleen Erickson and Pauline Hill from Dickinson County Parkinson Society



Standing, Robert & Gwen Willis Seated, Doug and Janet Whitaker

#### 2017 Annual Facilitator Training in Bay City

The Michigan Parkinson Foundation held its annual support group leader training program in April 2017 in Bay City. We have 71 support groups throughout Michigan and the leaders and a partner are invited to a two day training program. We provide updates on Parkinson's treatment options, exercise options, sharing best practices and leadership skills. We had a wonderful program learning and laughing together, bonding and making new friends. We thank the planning committee, and all the support group leaders, speakers and sponsors who drove through some horrendous weather to join us. Special thanks to our speakers who shared their time, talent and expertise:

Kelvin Chou, MD, University of Michigan STIM program

Micheal Shafer, PhD, PAR Rehab Services

Jennifer Hirsch, LMSW

 $Stuart\ Blatt,\ PhD,\ PT$ 

Ali Woerner, Co-Artistic Director of Take Root

Carol Schram, Rock Steady Boxing

Kate Schulz, Samaritas Affordable Housing of Cheboygan

Sara A. Schimke, Jaffe Raitt Heuer & Weiss, P.C.

Chris Sheridan, BSN, RN, Abbvie



Ali Woerner from Take Root, Stuart Blatt, PhD, PT and Carol Schram, Rock Steady Boxing

#### The speaker's presentations are posted to the MPF YouTube Channel.

Thank you Carole Briggs from the Jackson Support Group for serving as our photographer and Merry O'Connell for the beautiful centerpieces. Special thanks to Kate Hodgkins, Mary Griffore, and Laura Zeitlin for taking time off work to volunteer and help wherever needed at the conference. THANK YOU ALL!

#### **NEW SUPPORT GROUPS**

#### **MACOMB**

We are pleased to welcome the Macomb Support Group, facilitated by **Donna Zimny, RN**. The group meets the 2nd Friday of the month, at 5:00 pm, at Beaumont Macomb Center, 15979 Hall Rd., Macomb, MI 48044. Contact Donna at 248-964-8786 for details on upcoming meetings.



Cheboygan - Chelsea LaLonde
Thank you to Kate Schulz, who is leaving in August

Grand Rapids Hauenstein – Margaret Szarowicz, LMSW

Grand Rapids – Jody Van Halsema, RN, BSN Thank you to Allison Hondred, RN, BSN

Hillsdale - Cheryl Schlachter Thank you to Laura Elliston, RN

Lansing Caregivers - Karen Petersmark
Thank you to Sylvia Rundquist and Clarence Suelter

MovingUP Together – Tim Andersson Thank you to Laura Goring

Negaunee/Marquette County - Kristy Malmsten Thank you to Brittany Etelamaki, SW

Thumb Area (Bad Axe) – Susan Arthur Thank you to Merry O'Connell, RN

Tri-County Saginaw – Faith LaPonsie
Thank you to Martin Mann

# In Memoria



Ruth and Julia

#### **RUTH BUTLER**

died at age 90 on September 30, 2016. A registered nurse, Mrs. Butler was a tireless fighter and advocate for those affected by Parkinson's disease. Her husband, Pierce Butler was diagnosed with Young Onset Par-

kinson's disease when he was 36. She cared for him as his health deteriorated until his death at the age of 77, all the while working and volunteering.

For more than 20 years, Mrs. Butler was facilitator of the Western-Wayne Parkinson's Support Group, conducting monthly meetings in Livonia to provide information, doctor referrals and fellowship for patients and caregivers.

Daughter Julia Wall of Westland said, "Her dedication to her husband was extraordinary, and from that she became a Parkinson's warrior for all those affected. She left a forever footprint in the Parkinson's world."

"She excelled at care; the kind that always asked how are you feeling?" said Dr. Peter LeWitt, Wayne State University Professor of Neurology and Director of the Parkinson's Disease and Movement Disorders Program with the Henry Ford Health System.

Daughter Liz Kalinowski of Canton accompanied her mother on a trip to Washington D.C. with the Parkinson's Action Network. "We went there so she could testify before Congress to request funding to promote awareness and get more information out to the medical community," Kalinowski said. "At the hearing, Michael J. Fox sat on one side of her, and Muhammad Ali was in his wheelchair, sitting on her other side. When she finished testifying, Ali was clapping and she got a standing ovation from all the people, including Michael J. Fox." Mrs. Butler's achievements were formally recognized by the Michigan Parkinson Foundation. She received the Dr. Raymond Bauer Humanitarian Award.



Paula and Larry Foy

#### LARRY FOY, APRIL 6, 2017

Larry Foy, passed away on April 6, 2017 at the age of 80. Larry and his wife, Paula, had a close connection to Michigan Parkinson Foundation from the time he was diagnosed with Parkinson's disease in 2004. Larry and Paula always worked as a team whether they were volunteering at MPF Offices, contacting local businesses for Silent Auction Items for "A Night of a Thousand Stars" Gala, or getting friends and family

to join their team for the St. Clair Shores "I Gave My Sole for Parkinson's" Walkathon. Larry and Paula were active members of the Rochester Support Group for many years. Larry's most recent triumph was participating in the Rock Steady Boxing program at The Boxing Rink in Troy. He had a pretty good right jab! Larry always had a smile for everyone and is missed greatly by all!



Judy and John Waller

JOHN WALLER, age 74, passed away on Tuesday, August 1, 2017 after having Parkinson's Disease for 16 years. John earned a Bachelor's Degree in Electrical Engineering from General Motors Institute, a Master's in Electrical Engineering from the University of Colorado, and a Master's in Math from the University of Michigan. After 37 years of service, John retired from

General Motors. In retirement, John continued to lead an active life and loved the outdoors. He ran the Boston Marathon, skied the American Birkebeiner and took seven trips to the Boundary Waters of northern Minnesota and Canada. He especially enjoyed a two-week trip he took with his son around Hunter's Island in Canada. John was an active member of the Ann Arbor Bicycle Touring Society and did publicity for One Hell of a Ride for many years.

John, with his wife Judy, led the Ann Arbor Parkinson's support group for 4 years. Helen Martin, Secretary of the Ann Arbor Support Group reports that John and Judy were instrumental in growing the size and reach of the support group. Additionally John initiated free weekly exercise and music therapy classes for people with Parkinsons. The Ann Arbor group continues to be among the stronger and more active groups in the state. John was a kind, curious, adventurous, humorous, and intelligent man who will be missed by all whose lives he touched.



#### **VINCE MARINO, FEBRUARY 9, 2017**

Vince Marino, a longtime volunteer for the Michigan Parkinson Foundation passed away on Thursday, February 9, 2017 at age 64. Vince was diagnosed with Parkinson's disease at age 50. Upon learning of his diagnosis, Vince dedicated his life and considerable energy to the Parkinson's community. He served on the volunteer Board of Directors for several years and initiated the "I Gave My Sole for Parkinson's" walk in St. Clair Shores. Additionally, he was very active in the Young Onset PD Support Group in St. Clair Shores. Vince loved to organize events,

and his mind was always thinking ahead to planning the next event.

# 2017 Lansing "I Gave My Sole for Parkinsons" -- NEW LOCATION!

We moved the Lansing Walk/Run to Michigan State University's Campus. It will take place in front of the Auditorium on Saturday, September 16, 2017 at 10:30 am. Parking will be easy! There are two large outdoor parking lots directly across the street from the auditorium.

Walkers will have a choice of a one mile or three mile route. Instead of walking on the high school track, we will walk on a paved, flat, even bike path. We will continue to offer a 5K competitive timed road race for all runners.



#### **EAST LANSING**

September 16, 2017, Michigan State University Campus 542 Auditorium Rd. (at Farm Lane), East Lansing, MI 48824

# 2017 Kalamazoo "I Gave My Sole for Parkinson's"

The Kalamazoo walk will take place on October 21, 2017, at 10:30 am. We offer a one and three-mile route through the beautiful Celery Flats Historical Park. It should be the peak weekend for our Fall colors. We do not offer a run at this location.

Kalamazoo/Portage Celery Flats Historical Area 7335 Garden Lane, Portage, MI 49002

# Financial Support for Respite Care available

Financial support is available for family members who need a break and cannot leave their loved one with Parkinson's unattended. MPF can provide financial assistance of up to \$360 per year for an adult respite care center. To apply for this program, you or your spouse must have Parkinson's disease, be a resident of Michigan and attend an adult respite care program in Michigan. For more information, contact MPF 248-433-1011.

# Financial Support for Medication Assistance

MPF can assist people with Parkinson's disease who meet financial criteria (low income) obtain some relief for medication costs. Qualified individuals must be a Michigan resident. We take into consideration not only annual income but how much you pay out of pocket for medical bills. Once you qualify, your medications will be mailed directly to you. For more information contact MPF 248-433-1011.

## 2017 Metro Detroit "I Gave My Sole for Parkinson's"

We made some changes this year. In the past we had two walks in the Metro Detroit area; one walk in St. Clair Shores and one in Northville. We combined the walks and



**CORPORATE SPONSORS:** We cannot present Parkinson's educational programs or fundraising events like the walks or the Moon River Cruise without the help from our valuable corporate sponsors who help underwrite the cost of the event or program. A complete list of all sponsors will also be listed in the December issue.

#### PRESENTING SPONSOR:

Ray Laethem Motor Village

**PREMIER SPONSORS:** Abbvie John & Marlene Boll Family Foundation Magna, Michigan Neurology Institute

**GOLD SPONSORS:** Ally Financial, Gentherm, Henry Ford Health System Department of Neurology, Jaffe Raitt Heuer & Weiss, P.C, KBC Tools, Lundbeck, Kroger Company of Michigan, Michigan Head & Spine, Making the Turn Against PD. St. John Providence/Ascension. Team Fox Detroit, Tocco Mannino, Tom & Carol Cracchiolo, US World Meds

SILVER SPONSORS: Acadia, Fox Run, GE Healthcare, IMPAX Labs, Lundbeck, Neil King Physical Therapy. Quest Research Institute, University of Michigan STIM, Senior Helpers

PATRON SPONSORS: A Better Life Home Care, Abbott, Axxis Communications, Grant Millman, Medtronics, State Farm Insurance, Sterling Insurance, Steven & Tara Grekin, Wesley Orthodontics, Wayne State University School of Medicine, Department of Neurology

#### **HERO SIGN SPONSORS:**

Civitan Club of Pontiac and Shelia Bass

IN-KIND SPONSORS: Brandon Roux. WDIV Local 4 Meteorologist, Absopure Water Company, Biggby Coffee, David Bartczak, Canes for a Cause Bob Leffler, Chuck Furchak, Commonwealth Café, Costco, Jet's Pizza, Kroaer, Meijer, Garv Brewer, Michigan Golf Carts, New York Bagel, Papa Romanos Pizza, Ridley's Bakery Café, Rock Bottom Band, The Boxing Rink, Trader Joes, Walgreens, Warren Woods Public Schools

put all our efforts into one hopefully larger walk and called it the Metro Detroit "I Gave My Sole for Parkinson's." We held the walk at the Birmingham Seaholm High School on May 20. We had more than 860 people walking and raised \$140,000. We are thrilled with the results and owe it all to our generous supporters.

**NEW THIS YEAR!** Team captains who

raised \$5,000 or more received their own canopy tent which was a great way to gather their team together. Additionally special VIP breakfast goodies were provided in the tent by Ridley's Bakery.



- 1. RSB Troy at The Boxing Rink, Team Captains: Mike Martelli and Steve Femminineo raised \$12,108.55
- 2. Shakin' Not Stirred, Team Captain: Jennifer Traver raised \$6500
- 3. Team Boukamp, Team Captain: Marianne Boukamp raised \$5597
- 4. Team Clark, Team Captain: Jeremy Clark raised \$5820
- 5. Team Triumph, Team Captain: Karen Tajer raised \$5385
- 6. Heart & Sole, Team Captain: Patrick J. Sharpe raised \$5115

**HUGE KUDOS TO THE** INDIVIDUAL FUNDRAISERS. THE FOLLOWING PEOPLE RAISED \$3,000 OR MORE

<u>Name</u>	<u>Amount Raised</u>
Stephen Femminine	eo \$6,102.55
Marianne Boukamp	\$4,130.00
Jeremy Clark	\$3,905.00
Bill Pettibone	\$3,618.00



Team Triumph





# **Hero Signs**

Those individuals or team captains who raised \$500 or more were eligible to order a Hero Sign. We lined the first quarter mile of the route with the Hero Signs.

It was emotional watching the families stop to pose with their Hero Sign. It was a big hit and next year, we hope to have 100 signs lining our route.



Uncle Joe – Team Rettig's Hero



Hero - Lorraine Applebaum

#### Meet Jennifer Traver, 2017 Metro Detroit Walk Honoree

"At the age of 42, after experiencing a tremor in my left pinky, I was diagnosed with Young Onset Parkinson's disease. My initial thoughts were shock and fear, as this diagnosis never crossed my mind. I knew nothing about Young Onset Parkinson's Disease. I soon



learned that the diagnosis of Young Onset Parkinson's disease is the same as idiopathic, or typical, Parkinson's disease except for the age of the patient. When an individual

Jennifer Traver and Team with Hero Sign

is diagnosed with PD before the age of 50, the disorder is called Young Onset Parkinson's disease.

Initially, my first concern was my children and how my disease would impact their lives. I immediately started researching online and found the Michigan Parkinson Foundation's website to be particularly helpful. This helped me wrap my mind around what was happening to my body, and to understand how to manage my symptoms. The two most challenging parts of my day are the beginning and the end. In the morning I wait for my medications to take effect and then at the end of the day when I go to bed, my goal is to fall asleep quickly and stay asleep until morning....I am still striving for this goal.

While living with Parkinson's disease can be challenging, I have never asked the question, Why? With the help of my faith and my very supportive family and friends, I knew I would get through this. From the very beginning of my Parkinson's diagnosis, the Michigan Parkinson Foundation has always made me feel as if I am not alone. Their guidance, compassion and willingness to help anyone with this disease has been instrumental in helping me and others cope on a day-to-day basis. The MPF has inspired me to keep on moving. It has brought me hope and insight into this disease. Rather than feel sorry for myself, I am determined to make something positive out of my situation. I am using my passion to provide means for continued awareness and research for a possible cure."

#### A Golden Anniversary to Celebrate - Levodopa and Parkinson's Disease

(cont. from page 1)

Although the pharmacological concept of levodopa as a direct precursor of dopamine seems logical, there is actually greater complexity to this drug. Levodopa has additional actions in the nervous system that are means unrelated to the generation of dopamine. Outcomes after chronic therapy with levodopa also can be puzzling, in that some patients start to experience inconsistency of benefits or involuntary movements (dyskinesias or dystonia). Not all patients experience these problems, and the risk factors for acquiring them are still poorly understood. We don't know how to prevent dyskinesias other than by avoiding the use of levodopa altogether, which would be a bad idea considering all the benefits it can offer. There isn't sufficient evidence to recommend a plan for holding back on adequate levodopa dosing (that is, less than the amount a patient needs for ideal relief of PD symptoms). Another long-standing controversy pertains to combining levodopa with drugs classified as dopaminergic agonists: pramipexole, ropinirole, or rotigotine. In the past, several inconclusive studies were carried out to determine if combination therapy might help to prevent the development of dyskinesias. It now seems clear that the use of dopaminergic agonists doesn't seem to confer any improved outcomes, although these drugs can be quite useful when added to levodopa for enhancing its effects. Involuntary movements developing during chronic therapy with levodopa are sometimes more feared than they should be, since they can be guite mild (and only one-third or fewer of chronically-treated patients ever develop them). The use of amantadine can block dyskinesias for some patients, and adjusting levodopa dosing can also lessen problematic dyskinesias if they occur.

Another concern about when to start levodopa is sometimes encountered by patients trying to learn about the drug: this is the mistaken notion that levodopa has only a limited duration of action before it loses its effectiveness. Often, periods of no more than 5 years have been cited for such an outcome, but there is no evidence for this. Other misinformation about levodopa includes fears that it is potentially toxic and, therefore, should be delayed in its start and dosing minimized. Again, this widely-held but incorrect notion sometimes appears on the Internet or even in advice given by physicians. There is no substantiation for many concerns about the safety of levodopa and, hence, no reason to be fearful of using this important PD therapy.

The major fault with levodopa is the short-duration of effect and inconsistency of uptake from oral administration. These problems become evident for some patients within three years after onset of this drug and are associated with frustrating experiences of "off" states, sometimes less than predictably throughout the day. Factors that interfere with regular uptake of levodopa include the influence of meals (and sometimes their protein content). Because of its rapid clearance from the bloodstream after oral dosing – for some patients, as short as  $2\,\frac{1}{2}$  hours – a treatment schedule

with multiple daily dosings can be necessary. There is no absolute limit to the daily intake of levodopa; in its typical carbidopa-levodopa 25-100 formulation, up to 12 tablets per day might be necessary for optimal symptom control. Ideally, this medication should be adjusted to gaining maximal control of PD symptoms, and for many patients, experimentation with increased dose may be a good idea. Patients should keep in mind that levodopa doesn't help all of the problems of PD – forward flexed posture, imbalance, "freezing of gait", and speech impairment are examples of its limitations. Nevertheless, under-medication with levodopa is a common missed opportunity for maximizing benefit with this therapy.

Longer-acting formulations of carbidopa-levodopa have been a long-term goal of improving treatment outcomes. Sinemet CR® and Stalevo® were developed for this purpose, but these products often fail to deliver extended relief with levodopa. Another controlled-delivery formulation, Rytary®, was developed to serve this need. Though effective for many patients, it sometimes presents a challenge for finding the optimal crossover from a prior immediate-release carbidopa-levodopa regimen, and the cost of its co-pay with some medication insurance plans can be substantial. Intestinal infusion of carbidopa-levodopa (Duopa®) in liquid form by pump is another option for extremely problematic motor fluctuations. This involves inserting a tube into the stomach through the abdomen, and so is reserved for the most severe problems. Fortunately, the pharmaceutical industry has been active at improving ways that levodopa can be delivered. Currently under development (and in clinical trials at Henry Ford Hospital and other locations) are a long-acting formulation of carbidopa-levodopa (the Accordion Pill) and a subcutaneous infusion of carbidopa-levodopa in a liquid formulation. Also under development is an inhaled version of levodopa that can be rapidly absorbed by inhaling it as a rapid means for recovery from an "off" state. Other research into ways to deal with the irregularity of levodopa effect are ongoing. Of course, we need to understand more about how levodopa works so that the initial ideal experience most patients have with this drug (which generally is without dyskinesias or fluctuations in benefit) could be continued lifelong.

In summary, levodopa is a naturally-occurring substance that for a half-century has offered PD patients a means for return from the discomforts and disabilities of this disorder. For those not well controlled with this drug in its current forms, new products may make life with PD a little bit easier. Ways to lessen its possible side-effects are also the topic of ongoing research studies.

# 2017 Symposiums

Parkinson's Symposium in the Upper Penninsula

Parkinson's Symposium in Grand Rapids

September 22, 2017 8:00 am – 3:00 pm

Bay College Iron Mountain 2801 North US 2 Iron Mountain MI 49801

Parkinsons Symposium in the Upper Penninsula will focus on exercise and its impact on PD symptoms

Featuring David Zid, BA, ACE, APG Co-founder of Ohio Health Delay the Disease.

Lori Guyton, MD, Board Certified AB Psychiatry and Neurology from southern Illinois

Patti Peterson, MD Dickinson Neurology Associates,

Tracy Blagec, Chaplain at Oscar G. Johnson VA Medical Center

Sara Gunville, DPT

906-774-8547 or 906-302-3000

Presented By:

Parkinson's Society of Dickinson County Area

For more information e-mail Pauline Hill at tiita61@yahoo.com or call 906-774-0332



8:00 am - 3:00 pm

Van Andel Research Institute 333 Bostwick Ave. NE Grand Rapids, Michigan

AGENDA FOR PATIENT TRACT

8:45 AM: Welcome by MPF Board member

9:00 AM: Updates in Parkinson's Disease Research
Patrik Brundin, MD, PhD
Professor and Director of the Center for
Neurodegenerative Science, Jay Van Andel
Endowed Chair in Parkinson's Research

10:15 AM: Vigorous Exercise as a Neuroprotective Strategy in Parkinson's Disease Eric Ahlskog, MD, PhD, Mayo Clinic Professor of Neurology, Mayo Medical School Mayo Clinic Neurology - Movement Disorders

11:30 AM: Managing Non-Motor Symptoms of Parkinson's

Christos Sidiropoulos, MD, Associate Professor Department of Neurology & Ophthalmology Movement Disorders Clinic, MSU

12:30 PM: Lunch buffet provided

1:15 PM: Mental Health Issues, Coping with
Anxiety, Depression and Sleep Issues
Barbara Fisher, PhD, BSM Licensed
Psychologist/Neuropsychologist Board
Certified Behavioral Sleep Medicine

2:15 PM: The Role of Rehabilitation in Managing Parkinson's Disease

Kim Paszkowski, MSCCCSLP / LSVT Certified Katie Dabkowski, PT, DPT / LSVT Certified Judy Overmyer PT / LSVT Certified Mercy Health, Hauenstein Neurosciences

The program includes a buffet lunch. Registration fee is \$15 per person. Call the Michigan Parkinson Foundation at 800-852-9781.





30400 Telegraph Road, Suite 150 Bingham Farms, MI 48025 (248) 433-1011 (800) 852-9781

Web site: www.parkinsonsmi.org

#### MPF provides the following services to those with Parkinson's and their families:

More than 71 Affiliated Support Groups • Medication Assistance • Informational Literature Adult Day Care Funding • Neurologist & Community Referral • Educational Programs • Advocacy Consult your medical providers before acting on information in newsletter articles. MPF publications offer information intended to be useful to people with Parkinson's, their caregivers and families, and the professionals who assist them, but they are not a substitute for qualified medical advice.

YOUR GENEROSITY IS GREATLY APPRECIATED. PLEASE HELP US NOW! NO MATTER HOW LARGE OR HOW SMALL.

Return to MPF, 30400 Telegraph Road, Suite 150, Bingham Farms, MI 48025, or donate on-line at www.parkinsonsmi.org

PLEASE SEND INFORMATION ON:	PLEASE CONTACT ME ABOUT:
— How I can become an exclusive member of the Michigan Parkinson Foundation's <b>CLUB 500</b> — Parkinson's Disease	<ul> <li>How I can make a Recurring Donation (weekly, monthly, etc.)</li> <li>How I might make a gift to MPF in my will, life, insurance or other special means which may have tax advantages.</li> </ul>
Enclosed is my gift of \$ VisaMastercard Discover AMEX  Account # exp  Card Security Code: Last 3 digits on back of card (4-digits on front of AMEX)  In Memory of  In Honor of  Special Occasion of  Please notify the following person of my gift:	Citystatezip  County  Phone I want to receive further mailings:

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