

MESSENGER

WINTER 2014

Exciting things are happening in Michigan!



UPCOMING EVENTS

MARCH 10-11

Annual Facilitator Training

APRIL

Parkinson's Awareness Month

JUNE

Thursday, 6/5

Grand Traverse Summer Four

I Gave My Sole for Parkinson's
 Walk-a-thon and 5K Runs

Saturday 6/7

Eastside (St. Clair Shores)

Sunday 6/8 Westside (Northville)

Friday, 6/13 -- Making the Turn
 Against Parkinson's Golf Outing -
 Williamston

AUGUST

I Gave My Sole for Parkinson's
 Walk-a-thon and 5K Run

Saturday, 8/2 -- Alpena

Saturday, 8/23 -- Kalamazoo

*Check website for additional
 educational programs and
 regional conferences. Ask to be
 placed on email list to receive
 monthly eblasts*

CONTENTS

MR-guided Focused
 Ultrasound Surgery FAQs 1, 7

Board/Prof. Advisory Board..... 2-3

Messages: Chairman / CEO ... 4-6

Looking for Clues of PD 8

Care for the Caregiver..... 9

Fundraising for Parkinson's .. 10-13

Support Groups 14-18

Educational Programs 18

Early Intervention in PD..... 18

Choosing an Exercise Program 19



30400 Telegraph Rd. Suite 150
 Bingham Farms, MI 48025
 (800) 852-9781 • (248) 433-1011
 Fax: (248) 433-1150
 www.parkinsonsmi.org



JASON M. SCHWALB, MD
 Neurosurgeon
 Surgical Director, Move-
 ment Disorder & Com-
 prehensive Epilepsy
 Centers, Henry Ford
 Medical Group; Clinical
 Instructor, Department
 of Neurological Surgery,
 Wayne State University
 of Medicine; Member,
 MPF Professional
 Advisory Board



PARAG G. PATIL, MD,
 PhD, FAANS,
 Neurosurgeon,
 Co-Director, Movement
 Disorders Program
 and Psychiatric Neuro-
 modulation Program,
 University of Michigan;
 Assistant Professor,
 Departments of Neuro-
 surgery, Anesthesiology
 and Biomedical Engi-
 neering, University of
 Michigan Member, MPF
 Professional Advisory
 Board

MR-guided Focused Ultrasound Surgery FAQs

WHAT IS MR-GUIDED FOCUSED ULTRASOUND SURGERY?

MR-guided Focused Ultrasound Surgery (MRgFUS) is a new technology to treat abnormal areas of the brain involved in a variety of different neurologic diseases. Since the 1950s, surgeons have treated patients with tremor, Parkinson disease, and other disorders by intentionally creating small strokes (lesions) in the brain. One common application was the creation of a lesion in an area of the brain called the VIM thalamus to treat tremor (thalamotomy). Traditionally, this has been done by inserting a probe the size of a strand of spaghetti into the VIM thalamus and precisely heating the tip. MRg-FUS accomplishes the same thing by focusing beams of ultrasound energy to create a lesion in the same location, but without needing to drill a hole in the skull and insert a probe. MRgFUS is similar in concept to stereotactic radiosurgery, e.g., Gamma Knife®, in that multiple energy waves are applied from different directions, all converging on a single point, just like using a magnifying glass to burn a leaf.

Using focused ultrasound to create lesions in the brain was explored in the 1950s, but the computer algorithms did not exist to deal with ultrasound energy bouncing off the skull. These issues seem to have been worked out by an Israeli company, InSightec (although they haven't quite figured out how to compensate for hair, so patients need to have their heads shaved for the procedure). They have developed ways of obtaining real-time feedback by performing special MRI sequences that monitor the temperature of a region of the brain while the ultrasound energy is being delivered. This allows the surgeon to monitor the targeted region and to adjust the amount of energy deliv-



(cont. on page 7)

Board Of Directors & Professional Advisory Board Elections

At the Annual Meeting of the Board of Directors and Professional Advisory Board on December 4, 2013, election results were announced. We are pleased to inform you of the following:

BOARD OF DIRECTORS OFFICERS:

Chairman: **Edwin B. George, MD, PhD**

President: **Peter A. LeWitt, MD**

Vice Chairman: **William Suminski**

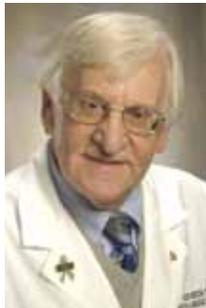
Treasurer: **Lawrence Millman, CPA**

Secretary: **Nanette Michaels**

NEW BOARD MEMBERS:

Welcome to **Todd Gardner!** Mr. Gardner has Young Onset Parkinson's. He is very actively involved in family life and in his current position as Director, Gaming and Licensing with the Michigan Lottery for the State of Michigan. He created a non-profit, *Making the Turn Against Parkinson's*, which focuses on holding annual golf outings to benefit the Michigan Parkinson Foundation. The first golf outing was held last June and was both successful and exciting. Mr. Gardner

has voiced interest in being on MPF's Technology Committee. We are thrilled that he has accepted a one year position.



Dr. Richard Merson was elected for a three-year term. He has been the Chairman of the Professional Advisory Board for the last 4 years and, as such, has held a seat on the Board. His turn as PAB Chair is completed and he was elected to a regular seat on the Board. Dr. Merson is a speech and language pathologist, Coordinator for Special Clinics and Research, Beaumont Hospital, and is an Associate Professor, Oakland University William Beaumont School of Medicine. He has been actively involved in MPF for over 20 years.



Donald McLean was elected to a three-year term. He is a Senior Account Executive for Airfoil Group in Southfield. Don's father has PD and he felt he could help us by volunteering to administer our Face Book page a year ago. The number of new "Friends" has increased significantly. Also a musician, he brought in his band, Cosmic Groove, to play at the Northville Walk-a-thon. Don's field is social media and public relations.



Susan N. Perry-Nolte was also elected to a three-year term. Susan is the Director of Marketing and Public Relations for McLaren Lap-er Region and has an extensive background in health care marketing, including at Botsford Hospital and St. John Providence Health System. She has been active with a number of non-profits.

Founding President, In Memoriam

Raymond B. Bauer, MD

Board Of Directors

Edwin B. George, MD, PhD, Chairman
 Peter A. LeWitt, MD, President
 William Suminski, Vice Chairman
 Lawrence Millman, Treasurer
 Nanette Michaels, Secretary
 Jeffrey Appel, Esq
 Tyrone Baharozian, Esq
 David J. Bartczak
 Robert Berlow, Esq
 Carole Briggs, RN
 Paul A. Cullis, MD
 Todd Gardner
 Linda Grap
 Suzanne Holguin, RN
 Joseph Katulic
 Nancy Knitter
 Shana Krstevska, MD
 Vince Marino
 Hon. Gail McKnight
 Richard McKnight, Esq
 Donald McLean
 Maxine Meach
 Richard Merson, PhD
 Merry O'Connell, RN
 Susan N. Perry-Nolte
 Ronald Slyter

Professional Advisory Board

Shana Krstevska, MD
 Chairman
 Glen Ackerman, MD
 Richard Berchou, PharmD
 Stuart Blatt, PhD, RPT
 Kelvin Chou, MD
 Timothy Collier, PhD
 Brian Cooper, OTR
 Paul A. Cullis, MD
 Doree-Ann V. Espiritu, MD
 Bradley Evans, MD
 Karen Freshwater, PA
 Edwin B. George, MD, PhD
 John L. Goudreau, DO, PhD
 Peter A. LeWitt, MD
 Richard Merson, PhD
 Parag Patil, MD, PhD
 Jason Schwalb, MD
 Denise Van Etten, RN
 John Waller, MSEE, MA, BSEE
 Laura Zeitlin, LMSW

Staff

Deborah M. Orloff, MPH, BSN, RN
 Chief Executive Officer
 director@parkinsonsmi.org
 Kelly Jacobone, Office Manager
 office@parkinsonsmi.org
 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



Todd Gardner receiving an award from Dr. George for donation of golf outing proceeds.

RE-ELECTED BOARD MEMBERS:

Jeffrey Appel, Esq.
Judge Gail McKnight
Ron Slyter

Dr. Peter LeWitt
Richard McKnight, Esq.
William Suminski

Many thanks to **Amy Jackson, Peter Hasbrook** and **Blake Johnson** who have come off the Board. Their commitment to their roles on Board of Directors has been invaluable. We know they will remain active with MPF in support groups and functions.



PROFESSIONAL ADVISORY BOARD (PAB)

Chairperson: **Shana Krstevska, MD**

Dr. Krstevska was elected as the new Chairperson following the expiration of Dr. Merson's term of office. She is a movement disorder specialist at Henry Ford Health System, with offices in Troy and Detroit. She is also an Assistant Professor of Medicine, Department of Neurology, at Wayne State University School of Medicine. Dr. Krstevska has been very actively involved in the Michigan Parkinson Foundation for many years on the PAB, giving lectures, consultation, and programs. We are proud to welcome Dr. Krstevska to this position.



New Member:

Karen Freshwater, PA-C, Bronson Hospital – Kalamazoo. Ms. Freshwater assumed her position as Physician Assistant for the Neurology Department 3 years ago and has demonstrated excellent skills both in care of people with PD and in program development. She has reinvented the Kalamazoo Support Group which is now one of the largest attended groups in the state, and has spearheaded new exercise programs and services for people with PD at Bronson Hospital – Kalamazoo. This past summer, she spearheaded the Regional Education Program which was held in Kalamazoo. Welcome to Karen Freshwater as a Member of the PAB!

Re-elected Members:

Kelvin Chou, MD, University of Michigan
Brian Cooper, OTR, Residential Home Health
Paul A. Cullis, MD, St. John Hospital
John Goudreau, DO, PhD, Michigan State University
Peter A. LeWitt, MD, Henry Ford Hospital
Denise Van Etten, RN, Michigan State University
Laura Zeitlin, MSW, University of Michigan

Make A Real Difference For Someone with Parkinson's

Whether you are an individual or a business, giving to the Michigan Parkinson Foundation helps ensure that we can provide programs and services for people with Parkinson's in Michigan. It is a gift that truly helps.

Contact the Michigan Parkinson Foundation offices for further information: (248)433-1011; (800)852-9781; via the Web site: www.parkinsonsmi.org or by email: info@parkinsonsmi.org

Many Thanks To All

The Board of Directors conveys their heartfelt thanks to all who have contributed in 2013.

We wish to acknowledge the following donors for their generosity during the last half of 2013:

John and Marlene Boll Foundation
Jacobson Jewish Community
Foundation – Arthur Braverman
Marietta Bretz
Ruth E. Catron Charitable Foundation
Sally Gereau
Jill Lochridge, in memory
of Dr. David Schwartz
Lee R. Miskowski
Rabahy Foundation

Special Community Fund Raising Corner

City of Livonia Employee Jeans Day
Community Financial Win for Charity
Gunnison Meadows Senior
Assisted Living Rummage Sale
Knights of Columbus #7545 –
Williamston
Krueger & Friends Foundation
Annual Golf Outing
Paula Artman Golf Outing
Phi Sigma Sigma- Zeta Omega Chapter
Rose Andre – Cookbook Sales



Edwin B. George, M.D.

Message from the Chairman

The Michigan Parkinson Foundation has truly had a banner 30th anniversary year! Below, CEO Debby Orloff describes all the advances and events that have made the year so exciting, including a new alliance, new programs, and more volunteers and supporters. It is truly wonderful to see our organization grow and expand its educational programs, activities and support groups, providing more assistance to more people affected by Parkinson's throughout Michigan. We have also been blessed this year with the resources we needed to push forward with these efforts, both through the tremendous efforts of all our supporters and volunteers, and some particularly generous gifts from a few benefactors. I sincerely hope that in the coming year we will be able to consolidate the progress we have made, and continue our expanded efforts. As we have expanded, our need for your support has grown, and I hope that all of us in Michigan can work together to continue to provide the programs and services that those with Parkinson's truly deserve.



Deborah M. Orloff

Message from the CEO

We have completed celebrating the Michigan Parkinson Foundation's 30th anniversary, and a special year it was. Since our inception in 1983, we have grown significantly to help address the needs of people with Parkinson's and their families, and it is because of the people and organizations that have stepped forward to help, the MPF has been recognized as one of the strongest independent Parkinson organizations in the United States. There have been many advances in understanding Parkinson's disease, and research is advancing. However, there is still much to do until the cure is found.

About twenty people from Michigan attended the Third World Parkinson Congress in Montreal in October 2013, which was attended by more than 3330 people from 64 countries. Attendees included researchers, practitioners of all health fields, and people

with PD and their families. There were 166 organizations from 44 countries who specifically deal with

PD, such as MPF, or professional organizations that provide related services! Clearly, concern for PD is world-wide. All of us felt the tremendous excitement of recent developments in research, and being able to learn from and interact with so many experts was inspiring. Networking with people from other organizations was stimulating and made all of us want to do more. Watch more than 25 hours of webcasts: www.worldpdcongress.org. The next Congress will be in 2016 in Portland, Oregon in 2016

The Board of Directors of MPF have enthusiastically approved our joining a newly formed association, called **Alliance of Regional Independent Parkinson Organizations (AIRPO)**,



Drs Cullis, Merson, LeWitt cutting 30th Anniversary cake at A Night of A Thousand Stars





MPF joined with the Alliance of Regional Independent Parkinson Organizations (AIRPO) to help benefit the greater Parkinson's community.

whose mission it will be to “benefit the greater Parkinson’s Community by providing a forum for sharing information, educating members, and facilitating collaboration and support among professional staff.” This group emerged from meetings held over the last few years by the Parkinson Disease Foundation with “independent” Parkinson organizations” in the US (not affiliated with any national organization) that are making a significant impact in their region. Current “members” are the MPF, Houston Area Parkinson Society, Parkinson Association of the Carolinas, Northwest Parkinson Foundation, and the Parkinson Association of the Rockies. The Parkinson’s Disease Foundation has agreed to provide the Alliance (AIRPO) with staff and communications support and coordination, and to underwrite the cost of at least one in-person meeting among members each year. MPF will remain independent and, by connecting with other similar organizations, we will build on our knowledge and skill to bring you best practices in programs, services, and organizational know-how.

We need to take the time to thank all of the people who have contributed to our efforts. This year, we looked back at those who helped to get MPF off the ground. The June Walk-a-thons honored a few of our first champions: Founding President Dr. Raymond B. Bauer’s four children recalled his dedication; Founding Chairman Tom Cracchiolo and second Chairman, John Boll, were interviewed on cable as well as being Honorary Chairpersons of the Eastside walk. We recognized the importance of support groups by honoring Betty Rusnack (Eastside), Ruth Butler (Livonia), two facilitators with longevity. We celebrated at the four Regional Education programs and Annual Facilitator Training with an Anniversary cake and slide presentation featur-

ing volunteers. In August, we held a 30th Anniversary party at the Steinway Piano Gallery of Detroit, celebrating past and present Board members, Support Group Facilitators, and major supporters. I personally want to thank everyone for their kind recognition of my role as a founding member and 30 year supporter. Dr. Peter LeWitt, MPF’s President, was honored at *A Night of A Thousand Stars* in November, as he embarks on his 30 years’ history with MPF.

MPF’s unsung heroes are the members of the Board of Directors and Professional Advisory Board who unselfishly contribute hundreds of hours, their professional expertise, connections, advice and financial and emotional support to the Michigan Parkinson Foundation. The majority of these individuals have been participating in MPF for well over 10 years, attesting to their commitment. The Board members attend quarterly meetings, head and participate on committees, such as Finance, Investment, Strategic Planning, Technology, and events, and help MPF staff in matters pertaining to the business aspect of running an organization. Several Board members, such as our Treasurer, Larry Millman, are available several times a week to assist with financial and operational issues. Six of the 2013 Board members are also Facilitators of support groups, and they put in countless hours organizing and interacting with their support groups. The majority of the members also have “regular” jobs, or they are contending with Parkinson’s disease.



Lavonne Upton at World Parkinson Congress (MPF’s display table)

Message from the CEO and Board Chairman

(cont. from page 3)

The Professional Advisory Board (PAB) members, four of whom are also on the Board of Directors, write articles, present talks at support groups and other educational programs, and make themselves available for consultation on medical issues. Also elected are 8 neurologists/movement disorder specialists, a prominent PD researcher, two neurosurgeons, a geriatric psychiatrist, gerontologist, pharmacist, nurse, physical and occupational therapist, speech and language pathologist, and a representative from the support groups. The PAB has consistently demonstrated their leadership and expertise in the Parkinson's field, this year publishing two position papers this year to guide MPF in promoting best practices of care for people with PD.

Every member of MPF's Board and Professional Advisory Board is committed to assisting the Parkinson's community. Michigan Parkinson Foundation is fortunate to have such dedicated individuals in leadership roles.

Those of you who have had personal contact with the MPF will heartily agree with me that the staff are truly amazing – and nice people to boot! **Kelly Jacobone** (Office Manager), **Diane Kraft** (Program Assistant), and **Meri Sheen** (Data Coordinator) are dedicated, highly competent, and a superb team. As demands are such that we need to expand programs and services, in 2014 we are planning to add two part time staff: one person to support our education efforts, and another to help with day to day operations.



I'd like to share with you what I think are some of our major accomplishments of 2013:

- Strengthening the support group system. There are now 60 affiliated support groups throughout Michigan. Some have expanded their programs to include groups for care partners, exercise, music therapy and socializing. MPF provides training for facilitators (100 people attended the 2013 annual Facilitator Training), grants, marketing, networking, consultation and educational materials for the groups.
- Expanding educational programs throughout the state including the highly successful Orientation programs, Regional Conferences and dvds of the talks which allow everyone the opportunity to “participate.”
- Improving the website, www.parkinsonsmi.org, providing better access to information on PD, MPF programs and schedules – and further enhancement is planned for 2014.
- Tackling important issues to improve management of care of people with PD – exercise and timely medication administration. The Position Papers have laid the basis for future educational efforts.
- Maintaining high quality services for people looking for information and support, especially through our Information and Referral program. We receive numerous phone calls and email requests for information and support, and we are able to respond to people personally and confidentially.
- Expanding *I Gave My Sole for Parkinson's Walk-a-thons* to a 4th site – Alpena! Not only are these fund raisers for programs, but opportunities for empowerment for people affected by PD. We now have plans for site number 5.
- Taking first steps in social media, thanks to the help of volunteers such as Donald McLean who is managing our Face Book and Twitter pages.
- Continuing to receive feedback that MPF is helping people and providing support. This is our mission and it is critical that we meet our objectives. The Board of Directors has developed a strategic plan that is solid and valid. We evaluate what we have accomplished regularly and work diligently to set up realistic goals that are pertinent. Your feedback is valuable!

***May 2014 bring you all health, hope and happiness.
Thank you for your support so we can help others!***



MR-guided Focused Ultrasound Surgery FAQs



(cont. from page 1)

ered to that area. Having the patient awake during the procedure allows the surgeon to adjust the target if the patient has side effects with a lower energy test lesion.

DOES IT WORK?

The group from the University of Virginia recently published their results in the *New England Journal of Medicine* in 15 patients with Essential Tremor who underwent MRgFUS lesioning in the VIM thalamus. All 15 patients had significant reduction of their tremor on the other side of the body 1 year after the MRgFUS thalamotomy with associated improvement in quality of life. Four had persistent tingling in either their lip or hand, one of whom found this uncomfortable. While this is promising, it is a single center experience and needs to be replicated.

WHAT ARE THE DIFFERENCES BETWEEN MRGUFUS AND DEEP BRAIN STIMULATION?

Deep Brain Stimulation (DBS) is essentially a pacemaker for the brain. In DBS surgery, a thin wire is inserted into a specific area of the brain and connected to a pacemaker battery. An electrical signal, which is weaker than a 9-volt battery, modulates abnormal signals passing through that region of the brain, resulting in an improvement in symptoms. DBS parameters can be adjusted by remote control, so that an optimal balance between symptom improvement and side effects can be achieved. By contrast, radiofrequency lesioning, stereotactic radiosurgery, and MRgFUS create permanent and irreversible changes in the circuitry of the brain. Instead of pacing the brain signals, some of the cells or fibers responsible for the symptoms of the disease are destroyed.

WILL FOCUSED ULTRASOUND REPLACE DBS FOR PARKINSON DISEASE (PD)?

This is very unlikely. There is currently a trial going on for focused ultrasound thalamotomy for people with PD (<http://clinicaltrials.gov/ct2/show/NCT01772693>). We would expect these patients to have similar results to those patients with PD who have undergone traditional thalamotomy with a radiofrequency probe, i.e., reduction in tremor, but not in slowness of movement, rigidity, on-off fluctuations or levodopa-induced dyskinesias. In addition, we know that patients with bilateral tremor are better off with bilateral DBS than bilateral thalamotomy: DBS has a much lower risk of speech problems.

MRgFUS could be used in other areas of the brain, such as the globus pallidus pars interna (GPi) or the subthalamic nucleus (STN), areas that, when lesioned or stimulated, lead to improvement in tremor, slowness of movement, rigidity, on-off fluctuations and levodopa-induced dyskinesias on the opposite side of the body. However, we know from studies done in countries that cannot afford DBS, that 15-20% of patients undergoing lesions of the STN develop uncontrollable movements (hemiballism). The risk of speech problems with bilateral pallidotomy is also higher than in patients undergoing bilateral pallidal DBS.

While lesions are attractive, due to the fact that there are no hardware-related complications and there is no need for programming or maintenance of a DBS system, the ability to adjust stimulation parameters to reduce side effects is lost. Once a lesion is made, whether by a radiofrequency probe, focused ultrasound or Gamma Knife®, there is no going back.

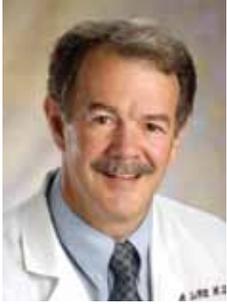
WILL FOCUSED ULTRASOUND REPLACE STEREOTACTIC RADIOSURGERY (E.G., GAMMA KNIFE®) THALAMOTOMY?

Perhaps for some patients. MRgFUS has several advantages over stereotactic radiosurgery. With focused ultrasound, the target can be adjusted based upon a test lesion, which is not the case with Gamma Knife® thalamotomy (although one of the patients in the *New England Journal* report had uncomfortable, permanent numbness in spite of a test lesion). There have been cases reported of severe complications associated with inaccurate targeting with the Gamma Knife®. In addition, the benefits from focused ultrasound (as with traditional radiofrequency lesioning) are immediate, whereas a patient undergoing Gamma Knife® thalamotomy usually has to wait months to see any tremor reduction. However, Gamma Knife® lesions can be performed in people who are on blood thinners or have abnormal blood clotting, which is not the case for MRgFUS.

WILL MY INSURANCE COVER IT?

Not yet. Focused ultrasound is FDA-approved for treatment of uterine fibroids only. The current studies are research only. If this technology is found to be safe and effective and is approved by the FDA, it is unlikely to be widely available. The machine currently costs more than \$1,000,000 and can only be used with General Electric MRIs (GE owns a stake in InSightec).





PETER A. LEWITT, MD

Director, Parkinson's Disease and Movement Disorders Clinic, Henry Ford Hospital West Bloomfield; Professor of Neurology, Wayne State University School of Medicine; President, Michigan Parkinson Foundation and Member, MPF Professional Advisory Board

Looking Far and Wide for Clues of Parkinson's Disease (PD)

Recently, the research community has been exploring an expanding landscape of PD's identity. By this, I mean that there have been increasing opportunities to spot traces of this disorder beyond the territory of the brain. Some patients tell me that "every part of them feels the impact of PD"; about this, they may be correct. Recent research has provided evidence for PD elsewhere in the body, far beyond the several hundred-thousand nerve cells whose loss results in slowness of movement and other characteristic symptoms. One of the most exciting findings has to do with discovery of abnormal protein aggregations characteristic of those found in the PD brain but which are found in the lower GI tract. In one study, these protein accumulations developed several years before patients received the diagnosis of PD. These findings provide a fascinating insight into how PD might arise. Perhaps these changes in the colon are the earliest manifestations of the disease, arising years before the brain becomes affected with PD.

Two additional research observations also add further complexity to the puzzle. One intriguing finding is discovery that the abnormal protein aggregations (the name of this particular protein is alpha-synuclein) can travel from inside one nerve cell to another. This invasion of a neighboring cell, suggesting a cell-to-cell transmission like an infection, may be telling how PD advances. Another important observation is the particular brain region first to be affected in PD, which is located deep in the base of the brain. This brain region (called the dorsal

motor vagus nucleus) is connected to the colon by a nerve traveling this long distance. Is it possible that this connection (the vagus nerve) transmits the initiation of PD from the colon to the brain using the protein transfer mechanism? This question has been on the mind of many researchers. While there isn't yet a practical implication of these findings (and much more needs to be learned), they may lead to improved diagnostics for early stages of PD. Furthermore, preventative strategies for PD in the future might take aim at events taking place in the colon long before they arrive in the brain.

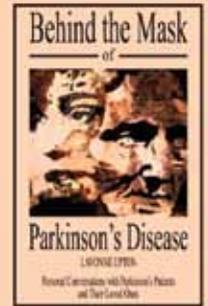
The connection between gut and brain is also of interest because PD patients have a propensity for constipation. This increased risk can even precede the onset of PD manifestations. Perhaps it is the evolution of alpha-synuclein protein aggregations in the PD colon that accounts for symptoms of constipation. Whatever the cause, PD patients need better treatments for this common problem. Currently, a new treatment for chronic constipation, RM-131 (<http://clinicaltrials.gov> [NCT01955616]), is under investigation by the Parkinson Study Group. This clinical trial is being conducted locally at the Henry Ford Hospital Parkinson's Disease and Movement Disorders Clinic in West Bloomfield. PD patients experiencing this problem and wishing to participate (at no cost) are invited to contact (248) 325-2452 for further information.

So, it may seem that PD – formerly know as just a "brain disorder" - is undergoing a bit of an identity crisis due to recent research. Other investigators have found that the heart also manifests subtle changes that may reflect the imprint of the disease. Researchers have also found that white blood cells, the retina, and certain components of cells all over the body have PD-specific changes, although the significance of these is not known. Clues that can enhance the early diagnosis and, ultimately, the cure of PD are needed and are being reported on a frequent basis. Let's hope that someone connects the dots and gets us answers fast!

Behind The Mask of Parkinson's Disease,

A New Book By Lavonne Upton

At the recent 3rd World Parkinson Congress in Montreal, many doctors from the podium said they want to listen to the voice of their Parkinson's patients. A good start would be to pick up the new book written by Lavonne Upton. A published author with PD and a member of the Rochester PD Support Group, Lavonne has



recently published a book entitled Behind the Mask of Parkinson's Disease. This book of interviews with Parkinson's patients, spouses, caregivers, and loved ones, gives an intimate view of those impacted by PD and how they have dealt with the challenges of the disease. The conversations include candid and heartfelt remarks about their feelings, coping skills, humor, and hopes for their future.

To order, send a check made payable to Behind the Mask for \$15.00 per copy, plus 6% Michigan sales tax, and \$4.00 for shipping and handling (\$1.00 per additional copy for shipping and handling.) Behind the Mask, P.O. Box 82365, Rochester, Michigan 48308. Email: ParkinsonsBook@comcast.net. Also available at www.amazon.com, wwwcreatespace.com, and www.behindthemas-kofparkinsons.com (website coming soon).



Caring for the Caregiver (part 2)



DENISE VAN ETTEN, RN
Member, MPF
Professional Advisory
Board; Movement Dis-
orders Coordinator
Michigan State
University

Caregiver burnout can have emotional, spiritual and physical consequences. Exhaustion, depression, anxiety and guilt may consume the caregiver. She/he may be irritable, negative, or forgetful and often becomes isolated from others. It is important to recognize needs early on so adjustments can be made to prevent burnout. Recognizing the need for support or services to prevent caregiver burnout can be challenging, but there is help available.

Communication is crucial. Discussing needs and lifestyle changes with the person with Parkinson's is essential. Ad-

ditionally, discussing needs and concerns with family members and friends can be helpful. Talking together about how to adjust your lives and finding ways to continue a healthy relationship is important for both the caregiver and the person with Parkinson's. Medical personnel, social workers and therapists can help foster these discussions or provide suggestions of services in your area. When more assistance and respite care are needed, you will have already established a support network.

There are available services through the Office on Aging for your county. Services include Project Choices/MI Choice Program, which sets up a nurse and social worker team to design a plan of care. There are respite services and Meals on Wheels. They also provide housing assistance and a Community Resource Directory. It is important to check on resources in your area and sign up for services early as many have wait lists.

Home care agencies and private duty services can provide aides to help with tasks like the morning/evening routines of getting showered and dressed.

Look for daycare programs or senior centers that offer on-site activities for a few hours or the entire day. Respite care can be provided through agencies to allow time for errands. Longer stays are available through assisted living and long-term care facilities.

Managing Parkinson's medications frequently throughout the day can be a daunting task. Some pharmacies provide a service where they set up bubble packs or medication boxes. Home care or private duty nurses can also set up medications and often have ideas for helping with timeliness of medications. Using a simple kitchen timer or setting alarms on a watch or cell phone are simple reminders for dosing times.

Simplify and prioritize things that need to be done. Recognize and delay tasks that are not as important or that can be done less frequently. Divide the labor by setting up a to-do list for both of you. Set up a schedule for tasks that need to be done daily, weekly or monthly. Take a break from tasks like washing dishes by using disposable tableware. Eat a meal out to take a break from meal planning, food preparation and cleanup.

Accept help when offered and don't hesitate to ask for help when needed. When family or friends ask what you would like for your birthday or holiday, ask for time, a meal or gift cards to housekeeping services or lawn services.

Consider attending a Parkinson's or caregiver's support group, if one is available in your area. Michigan Parkinson Foundation's website has a list of organi-

zations around the state. There may be caregiver support groups through other organizations for chronic illnesses that may also be beneficial.

Caring for a loved one is admirable, but can take a toll on your own health. You should not feel guilty for taking time to care for yourself. Meet a friend for lunch or coffee. Go to the movies. Take a walk. Recognize your own needs and take care of yourself!



Okemos Run Sponsors

Presenting: Anonymous

Platinum: Rush Trucking

Gold: UCB Pharma

Bronze: MSU Department of
Neurology & Ophthalmology,
Movement Disorders Clinic
Capital Imports (Honda)
Alice & Roy Erickson
O'Leary Paint

Media Sponsors:

HOM/CAM TV

WILX - TV 10

WSYM-TV FOX 47 Television

Lansing State Journal

Special thanks to

Guitar Center of Lansing

Committee

Jim Galloway, Chair

Ray Buch

Rose Mary and Roland Hubbert

James Jablonski

Alice and Gene Kenyon

Lori Mann

Michelle McDevitt

Denise Van Etten

Special recognitions: Top fund
raising individual: Roland Hubbert

Top fund raising team:

Thelen Acres

Overall race winners:

Male: Aaron Usher

Female: Audrey Dahlgren

FUNDRAISING FOR PARKINSON'S

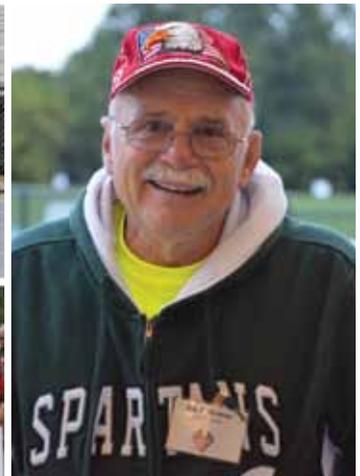
The Michigan Parkinson Foundation is an independent, non-profit organization dedicated to helping people with Parkinson's disease and their families. As you can see, MPF is growing with new support groups, new people, and new programs. It is essential for us to be able to raise funds in order to keep up with the needs and demands. Most of our revenues have been from private individuals and events. We wish to thank all of you who have been able to contribute financially to our efforts. Our annual campaign is still in process and we are planning additional programs for next year.

We could not be as successful were it not for the efforts of hundreds of volunteers who help organize fund raising events. Here is a brief summary of the second half of 2013.

I Gave My Sole for Parkinson's Walk-a-thons and 5K Runs

Since the last Messenger was published, two Walk-a-thons and 5K Runs were held: the fourth annual **Okemos Walk/Run**, outside of Lansing, and the first in Alpena.

The Okemos walk/run boasted a record attendance (500 plus 88 volunteers!) and revenues (\$40,000) this year, thanks to the efforts of the planning committee. This was Jim Galloway's first year as Chairperson of the walk and he did an excellent job. Somehow, this year there was an unusually special feeling that everyone experienced and commented about. It must have been magic. Many thanks to the committee and to the special Honorary Chairs: Rep. Joan Bauer, Peter Hasbrook, Dr. James Potchen and Denise Van Etten, RN. Entertainment was provided by James Jablonski (music), Michelle's Dance Studio, SOMEKO Singers, and Ben Dilday and Cindy McElroy (vocals). Brandie Yates of HOM/CAM TV was our emcee once again. Thank you to Okemos High School for sponsoring this beautiful location!



Photos by Subi Bhandari





The first annual *I Gave My Sole For Parkinson's Walkathon & 5K Run* was held in **Alpena** on a sunny, clear Saturday, August 24, 2013. More than 100 people attended and raised over \$6,500! Christopher Hippensteel won for overall fund raising individual (Mark Beegle will have to have his hair cut into a mohawk!); Team Gary! was the first place fund raising team, and the Thumb Area Support Group located in Bad Axe raised the most money as a support group. This

group held their own walk-a-thon to contribute!

There is something to be said about smaller towns, as the planning group would say. The enthusiasm was great! Entertainment was superb - the music and singing provided by Music 4 You and BK Soundtrack were outstanding. John Meek, Bagpiper, led the enthusiastic crowd around the stadium track. Delicious aroma of hot dogs, etc. emanated from the Girl Scout Troop 2056 concession. Velena Jones, WBKB TV reporter emceed, with comments from Honorary Chair Matt Poli (Principal of Alpena High School), Chairperson Jeanette Beegle, Co-Chair Kathy Brown, and Pastor Jim Gulish. Home Depot brought building kits for the children, who also enjoyed having their faces painted. Local businesses donated silent auction gifts which also brought in funds to be used by the support group. Special thanks to committee members: Elle and Jerry Button and Judy Poli. Top runners in the male and female category were Mike Wurtsmith and Tracy Bathgate.



I Gave My Sole for Parkinson's Walk-a-thons and 5K Runs will be held in 5 locations in 2014. We are seeking sponsors, donations, volunteers, and people who want to make these events exciting!

Saturday, June 7, 2014
South Lake Schools
Admin Complex,
St. Clair Shores, MI

Sunday, June 8, 2014
Northville High School,
Northville Township, MI

Saturday, August 2, 2014
Thunder Bay Jr High School,
Alpena, Michigan

Saturday, August 23, 2014
Kalamazoo NEW!!!!

September
date to be determined
Okemos High School



Photos by George Snedden

56th Annual Detroit Boat Show

Feb. 15-23
Cobo Center

TUESDAY, FEBRUARY 18

features the Michigan Parkinson Foundation! The day is captioned: *Don't Rock the Boat & Ladies Day*. Participating dealers will donate \$100 to the Michigan Parkinson Foundation for every boat sold. Ladies get in free.

The Boat show is held February 15-23 at Cobo Hall. Adult admission is \$12 and children under 12 are free with an adult. Discount tickets and hotel accommodations at the Courtyard by Marriott Detroit Downtown are available at www.detroitboatshow.net.

HOURS: Saturdays and Monday: 11 a.m. – 9 p.m.; Sundays: 11 a.m. – 6 p.m.; Tuesday through Friday: 3 p.m. – 9 p.m. Parking is available at Cobo Center and surrounding lots. The Detroit Boat Show is owned and produced by the Michigan Boating Industries Association (MBIA), the voice of boating in Michigan. Revenue generated from this event is returned back to fund boater's interests via MBIA's programs and services. **FOR MORE INFORMATION** visit www.detroitboatshow.net, or call 1.800.932.2628.

PAULA ARTMAN'S
ANNUAL GOLF OUTING,
FRIDAY, JULY 11, 2014,
IN RAY, MICHIGAN.
CONTACT PAULA AT
(586)749-6262



Making the Turn Against Parkinson's 2nd Annual Golf Outing, Friday, June 13, 2014 Brookshire Golf Club, Williamston

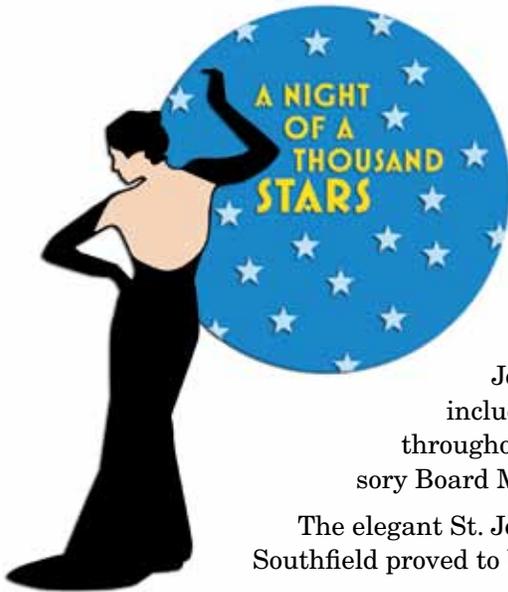
Last year's event was spectacular and Todd Gardner has added even more excitement with 2 raffles for golfers and non-golfers, including Spirit Airlines Las Vegas Package, golf packages at Hawk's Eye, Tullymore & St. Ives Golf, and Boyne, and an MIS NASCAR Package. Other prizes include rounds of golf, MSU football tickets, and more. Additionally, there is also a **MEMBER FOR A DAY RAFFLE**, where winners can golf at one of fourteen of the most prestigious private country clubs in Michigan including, Oakland Hills, Warwick Hills, Lost Dunes, Wyndgate, Wuskowhan, and more!

Take time to look at details of this special benefit and a very unique raffle for both golfers and non-golfers at: www.makingtheturngolf.com



Kathy Chockley held a bowling fund raiser in honor of husband Larry's 50th birthday, to benefit MPF and raised \$650

NIGHT OF A THOUSAND STARS



A Night of A Thousand Stars, MPF's annual benefit held on November 2, 2013 at St. John's Banquet & Conference Center in Southfield, celebrated not only people affected by Parkinson's disease, but our Thirtieth Anniversary! To top it off, Michigan Parkinson Foundation also honored its President, Dr. Peter LeWitt, who marks his 30th year as a vital part of MPF in January 2014.

Joining in on the festivities were 250 people, including representatives from many support groups throughout the state, Board Members, Professional Advisory Board Members, and friends.

The elegant St. John Armenian Church and Conference Center in Southfield proved to be a superb venue, serving excellent food. Enter-

tainment and dancing music was provided by The Henry Ford Big Band, an ensemble of 17 musicians who are world renown. The emcee was radio personality, columnist and celebrity spokesperson, Linda Lanci, back for her fourth year. The photographer was Subi Bhandari. All volunteered their time and talents to this event. Attendees raved about the evening - its warmth, the elegant atmosphere and exciting silent raffle prizes. All proceeds will be used for MPF's upcoming 2014 education and support programs.



Dr. LeWitt with Julia Gorham accepting award



If you need a soft shoe...



Night of a Thousand Stars raffle winner

Thanks to:

Presenting Sponsor:
Anonymous, in Honor of Larry Foy

Platinum Sponsor:
Neil King, Physical therapy

Media Sponsor:
MY Magazine

Volunteer Sponsor:
Comerica

Silver Sponsors
Anita & Ron Taylor
in honor of Lorraine Applebaum

Bodman Attorneys & counselors

Helping Hand Home Healthcare

Keller Williams Realty Lakeside

RICOH

Starla Zehr,
Oakland County Family Attorney

COMMITTEE

William Suminski, Chairman

Lorraine Applebaum

Carol Cummins

Larry Foy

Carol & Glen Kramarich

Connie McKee

Adele Pleatman

Liz Thebert

Photos by Subi Bhandari

ALPENA

3rd Monday 1:00 pm
Mark Beegle (989) 595-6463
1st United Methodist Church
167 S. Ripley Blvd., Alpena, MI 49707

ANN ARBOR

2nd Sunday, 1:30 pm, no meeting in Aug.
Teresa Bowers (248) 478-4779
Bruce Mabee (734)439-0059
St. Joseph Hospital, Ellen Thompson
Women's Health Center, Class 1, 2nd Fl.
(Look for parking lot S, then parking lot M)
5320 Elliott Drive, Ypsilanti MI 48197

Parkinson's Social Activities

3rd Sunday, various locations
Devorah Wolf (734)996-3934
Julie Wheaton (734)665-4088

Adaptive Exercise Class

Thursdays, 3:00 pm
Devorah & Barry Wolf (734)996-3934
Grace Bible Church, 1300 S. Maple,
Ann Arbor MI 48103

Music Therapy Sessions

Tuesdays, 3:30 pm
Devorah & Barry Wolf (734)996-3934
Grace Bible Church (as above)

BATTLE CREEK

Parkinson Support Group:

3rd Tuesday, 10:00 am
Young Onset: 2nd Thursday, 5:00 pm
Care Partners: Last Tuesday, 10:00 am
Anne Clark (269)441-0920
All meet at Burnham Brook Center
200 W. Michigan, Battle Creek MI 49017

BERRIEN COUNTY (ST. JOSEPH)

2nd Thursday, 3:00 pm
Barbara Ford (269) 429-3675
Lakeland Medical Center, Upton Center,
Conference Room #5&6
1234 Napier Road, St. Joseph MI 49085

CADILLAC

Support Group meetings are on hold
Contact Diane Patterson (231)779-9420

CALUMET

2nd Monday, 1:00 pm
Sarah Baratono, SW (906) 337-5700
Aspirus-Keweenaw Home Nursing
311 Sixth Street, Calumet MI 49913

CASS COUNTY/CASSOPOLIS

2nd Tuesday, 1:00 pm
Brenda Harris (800) 323-0390 ext 248
Cass County Council on Aging
60525 Decatur Rd, Cassopolis MI 49031

CHEBOYGAN

3rd Tuesday, 4:00 pm
Kate Schulz (231)445-1595
McLaren Northern Michigan – Cheboygan
Campus – 3rd Floor Conference Room
740 S. Main Street
Cheboygan MI 49721

DETROIT

3rd Tuesday, 1:00 pm
Kloretta Moore (313)289-4453
Ed Kinchen (313) 969-7440
Hannan House
4750 Woodward, Detroit MI 48201

Adaptive Exercise Class

Thursdays, 10:00 am
Kloretta Moore, (313)289-4453
Hannan House, 4750 Woodward
Detroit, Michigan 48201

DOWNRIVER

4th Tuesday, 7:00 pm
Emily Buzas (313)982-5604
Westfield Activities Center
2700 Westfield, Trenton, MI 48183

EASTSIDE

Joined with Grosse Pointe Farms

ESCANABA

2nd Tuesday, 3:00 pm
Mike & Diane Oxford (906) 428-2549
Fred and Ellen Chenail (906) 428-2055
Heirman Center, Room 912
Bay de Noc Community College
2001 N. Lincoln, Escanaba MI 49829

FLINT

3rd Thursday, 2:00 pm
Ethel Bence (810) 655-0313
Genesys Home Health
5445 Ali Drive, Grand Blanc, MI 48439

FRANKENMUTH

3rd Wednesday, 1:00 pm
Marilyn Bernthal (989) 652-2515
Independence Village Harmony Hall
255 Mayer Road,
Frankenmuth MI 48734

FRANKFORT

3rd Thursday, 2:00 pm
Fred Hough (231) 882-4865
Trinity Lutheran Church
955 James Street, Frankfort MI 49635

GAYLORD (OCCOA-GAYLORD)

4th Thursday, 2:00 pm
John Panci, Pam Carlson, RN,
Dona Wishart (989) 732-1122
University Center at Gaylord,
80 Livingston Boulevard,
Gaylord MI 49735

GLADWIN

1st Wed., 5:00 pm
Julie Wright, RN (989) 246-6291
Mid-Michigan Gladwin Hospital
Professional Building, Community
Education Conf. Room
609 Quarter Street, Gladwin 48624

GRAND TRAVERSE EVENING SUPPORT

1st Tuesday, 6:00 pm
Ted & Sharon Stark (231)862-3234
Belinda Garvon (231) 263-0500
Munson Community Health Center, Rm G
550 Munson, Traverse City MI 49686

GRATIOT COUNTY

4th Wednesday, 2:00 pm
Jen Cook, SW (989) 875-5246
Masonic Pathways
1200 Wright Avenue, Alma MI 48801

GROSSE POINTE FARMS

Last Friday, 10:00 am
Karen Leigh (586) 285-5232
Betty Durkin (313) 884-6131
Grosse Pointe United Methodist Church
211 Moross, GP Farms, MI 48236

HILLSDALE

1st Thursday at 3:30 pm
Helen Bordner (517) 849-9164
Kim Baker, RN (517) 437-2422
Hillsdale Co. Senior Center, Lower level
320 W. Bacon, Hillsdale, MI 49242

HOWELL

Last Tuesday at 4:00 pm
Connie Spiteri (810)355-8838
St. Joseph Mercy – Livingston
Meeting Room #1, 620 Byron Road
(Blue canopy door entrance)
Howell MI 48843

Adaptive Exercise Class

Thursdays at 1:00 pm
Jane Haessley (810)569-5055
1st Presbyterian Church
323 Grand River Ave., Howell, MI 48843

IONIA

3rd Thursday, 1:30 pm
Retta McCaul (616) 693-2121
Ionia Commission on Aging
115 Hudson, Ionia MI 48846

IRONWOOD

2nd Wednesday, 10 am
Adrienne Chase (906)932-6205
Danielle Grayson (906)932-5330 ext. 6050
Aspirus Grand View Hospital
N10561 Grand View Lane,
Conference Room B, Ironwood, MI 49938

JACKSON

2nd Tuesday, 7:00 pm
Carole Briggs, RN (517) 783-6527
disAbility Connection
409 Linden Ave, Jackson MI 49203
(between Prospect and 4th Street)
No meetings July, Aug., Dec.

KALAMAZOO

2nd Tuesday, 4:00 pm
Tiffany Hansard or
Stephanie Wagner (269) 341-7500
Bronson Lifestyle Improvement Center
6789 Elm Valley Dr, Kalamazoo MI 49009
Kalamazoo Care Partners
Contact Nancy Schullery (269)372-7241

LANSING CAREGIVERS' GROUP AND DIALOG GROUP

1st Wednesday, 1:00 pm
Barb Hasbrook (517) 324-0747
(Caregivers)
Ray Buch (517) 336-4121 (Dialog)
All Saints Episcopal Church
800 Abbott Road, E. Lansing, MI 48823



MICHIGAN PARKINSON FOUNDATION, AFFILIATED SUPPORT GROUPS - WINTER 2014
1-800-852-9781 or 248-433-1011 or www.parkinsonsmi.org

LANSING/EAST LANSING

3rd Tuesday, 6:00 pm 2nd Tuesday in Dec
Gene Kenyon (517) 694-7337
Valley Court Park Community Center
201 Hillside Court, E. Lansing MI 48823

LENAWEE COUNTY (ADRIAN)

1st Thursday, 1:30 pm
Dianna Oates (517) 673-3868
Carter Rehabilitation Center, Suite 3
1525 W. Maumee, Adrian MI 49221
No meetings July-August

LIVONIA (WESTERN WAYNE)

2nd Thursday, 7:00 pm
Ruth Butler RN (734) 421-4208
Livonia Senior Citizen Center
15218 Farmington Road, Livonia MI 48154

MANISTEE

3rd Thursday, 11:00 am
Jeannie Lewis (231) 723-8684
West Shore Hospital
Education Center, Room 1,
1465 E. Parkdale, Manistee MI 49660

MASON COUNTY (SCOTTVILLE)

3rd Wednesday, 10:00 am
Harv Buter (231) 757-0221
Senior Center
140 S. Main, Scottville MI 49454
No meetings Jan. or Feb

MIDLAND

3rd Monday, 7:00 pm
Sonja McCartney (989) 837-9762
MidMichigan Medical Center – Midland
Conference Room H1224
4000 Wellness Drive, Midland MI 48670

MID MICHIGAN YOUNG ONSET

3rd Tuesday, 7:00 pm
Joan Szczepanski (989) 893-1503
Call for location No meetings July-Aug.

MONROE/FRENCHTOWN

3rd Tuesday, 1:00 pm
Barbara Mazur (734) 243-6210
Senior Citizens Center
Frenchtown Senior Citizens
2786 Vivian Road, Monroe, MI 48162

MONTCALM COUNTY

2nd Thursday, 12:30 pm
Becki Hansen (616) 548-5428
Greenville Senior Center
715 S. Baldwin Street, Greenville 48838

**MOVINGUPTOGETHER: MPF
COMMUNITY FOR 50 AND UNDER**

3rd Thursday, 7:00 pm
Movinguptogether@gmail.com;
Laura Goring (734)449-2969
Salem United Church of Christ
33424 Oakland, Farmington MI 48335

MT. PLEASANT (ISABELLA COUNTY)

2nd Monday, 6:00 pm - Call to confirm
Maggie Brunette (989) 773-4833
Isabella County Commission on Aging
2200 S. Lincoln Rd, Mt. Pleasant MI 48858

MUSKEGON: PARKINSON'S POWER

1st Wednesday, 10:00 am
Holly Lookabaugh Deur, PhD, PT
(231)737-4374
Norton Shores Public Library
Community Room
705 Seminole, Norton Shores, MI 49441

NEGAUNEE/MARQUETTE COUNTY

4th Monday, 1:00 pm
Lindsay Juricek, SW (906) 475-6266
Negaunee Senior Center
410 Jackson Street, Negaunee MI 49866

NORTHEAST MACOMB

1st Thursday, 3:00 pm
Denise Klimaszewski, RN (586) 716-7384
Village of East Harbor
33875 Kiely Drive, Chesterfield MI 48047

**NORTHWEST OAKLAND – HURON
VALLEY-SINAI (COMMERCE)**

3rd Tuesday, 7:00 pm
Pam Niebrzydowski (248) 890-1784
Huron Valley Sinai Hospital
1 William Carls Dr Ground Floor A.
Conference Room, Commerce MI 48382
(enter at North Orchard Entrance)

NOVI/FOX RUN

1st Tuesday, 3:00 pm
Ruthann Lapham (248) 668-8633
Fox Run Ascot Music Room
41100 W. 13 Mile Road, Novi MI 48375

OWOSSO

2nd Wednesday, 7:00 pm
Karen Prussner, RN (989) 723-6901
Memorial Medical Arts Building
721 North Shiawassee, Owosso MI 48867

**PARKINSON'S DAISIES: A SOCIAL SUP-
PORT GROUP FOR WOMEN WITH PD
OR ARE CARE PARTNERS**

Meets in the metro Detroit area at a
restaurant or other locale. Call for
information on future outings.
Patty Meehan (248) 420-6342

PETOSKEY

4th Wednesday 2:00 pm
Suzanne Holguin, RN (231)347-3211
Friendship Center
1322 Anderson, Petoskey MI 49770

PORT HURON

1st Wednesday, 2:00 pm
Kelly DiNardo, RN (810) 987-5000 x2344
Port Huron Hospital Jefferson Building
1320 Washington, Port Huron, MI 48060

ROCHESTER

1st Wednesday, 7:00 pm
Pat Yarnold (248)759-4562
Nancy Knitter (248) 852-8464
Crittenton Hospital – North Addition, 2C
1101 W. University, Rochester MI 48307

Care Partner Support Group

Meets last Wednesday 1:30 pm.
Contact Nancy Knitter: (248)852-8464
Crittenton Hospital, Conference Room 2E
No meetings July, Dec.

Adaptive Exercise Class

Thursdays, 9:15 am
Nancy Knitter, (248)852-8464
St. Ireneus Hall, 771 Old Perch Road
Rochester Hills, Michigan 48309

ROYAL OAK

2nd Monday, 6:30 pm
David Bartczak (248) 755-8034
Dennis Cavanaugh (248) 683-1153
Wm Beaumont Hospital Adm. Building
Classroom 2 – lower level
3711 W. 13 Mile , Royal Oak MI 48073
No meetings July, Aug

THUMB AREA (BAD AXE)

3rd Tuesday, 12:30 pm
Merry O'Connell, RN,
Human Development Commission
(800) 843-6394; (989) 673-4121
Annette Johnson (989) 864-3779
Holiday Inn Express
55 Rapson Lane West, Bad Axe MI 48413

**TRAVERSE CITY
(GRAND TRAVERSE AREA)**

4th Wednesday, 10:00 am
Hettie Molvang (231)947-7389
Maxine Meach (231)947-1946
Traverse City Senior Center
801 E. Front Street, Traverse City 49686
***Tai Chi for Parkinsonian's
and their care partners***
2nd & 3rd Wednesday, 3:15 – 4:00 pm
Hettie Molvang (231) 947-7389
Traverse City Senior Center
801 E. Front St, Traverse City 49686

TRI-CITY/SAGINAW

2nd Thursday, 2:00 pm
Martin Mann (989) 797-3600
Wescourt Independent Living
4141 McCarty Road, Saginaw MI 48603

WARREN

1st Thursday, 2:30 – 4:00 pm
Exercise Classes: every Thurs. 4:00 pm
Nora Palanjian, PT (586)573-5123
St. John Macomb Hospital,
Medical Education Center
11800 E. 12 Mile Rd, Warren MI 48093
Add No meetings Jan. or July

WEST BLOOMFIELD

1st Wednesday, 7:00 pm
Linda Klein (248)592-2318
Jewish Family Service
6555 W. Maple, W. Bloomfield MI 48322

WEST BRANCH

2nd Thursday, 12:30 pm
Carol Gillman (989) 345-3010
Ogemaw Commission on Aging Sr. Center,
1528 S. M-33, West Branch MI 48661

**YOUNG ONSET OF
SOUTHEAST MICHIGAN**

2nd Monday, 6:30 pm
Patty Meehan (248) 420-6342
South Lake Schools
Administrative Building
23101 Stadium, St. Clair Shores MI 48080

At the end of 2013, 60 support groups were affiliated with the Michigan Parkinson Foundation, attracting an average of more than 20 people per meeting. This translates to an annual attendance of over 9000! Six new groups were started including one geared to people with PD who are under 50 years of age. Several groups have added additional monthly meetings and programs to encourage people to exercise together, socialize, and support special needs, such as those of care partners. The volunteer facilitators are truly dedicated, and the Annual Facilitator Training draws about 100 people to learn and share how to keep meetings pertinent and creative. We thank the 74 people who are involved as Facilitators, whose average length of time in this role is 4.9 years, the range being less than 1 year to 30 years. About 50% of the leaders are people with PD or their family members, and the remainder are health professionals including nurses, social workers and health educators. Many others assist each group as part of a planning committee.

Michigan Parkinson Foundation Welcomes New Support Groups:



Muskegon Parkinson's Power Support Group

Holly Lookabaugh Deur, PhD, RPT, who is the owner of Generation Care in Muskegon, has recreated a support group for the area around Muskegon County. Assisted by **Michelle Davis**, SL&T, and **Krish Schneider**, RPT, they had a tremendous turnout at the first meeting held in November, 2013 at Norton Shores Public Library. The group will meet the first Wednesday of each month at 11:00 am at the library. (photo at left)

Kalamazoo Care Partners' Support Group was recently organized by **Nancy Schullery**, whose husband has PD. At this writing, she was confirming date, time and place of future meetings. Please call Nancy at

(269)372-7241 for information. This group is working in close cooperation with the Kalamazoo Support Group held at Bronson's Lifestyle Improvement Center.

SUPPORT GROUPS THAT ARE DISBANDING

The **Eastside Support Group**, held in Grosse Pointe Farms, has disbanded since **Betty Rusnack** passed away. This group has merged with the Grosse Pointe Farm's Caring and Sharing Group, which meets the last Friday at 10:00 am at the Grosse Pointe United Methodist Church, 211 Moross.

The **Cadillac Support Group** is taking a hiatus. If anyone in Wexford County and surrounding area is interested in attending meetings, contact **Diane Patterson** (231)779-9420 at the Senior Citizens Center.

The **Monroe/Frenchtown Support Group** thanks **Michelle Grysko** for being the lead. Contact Barb Mazur (734)243-6210 for information about the group

NEW FACILITATORS

Ionia: Welcome to Retta McCaul. We want to thank Barb Sterling for her passionate efforts.

Midland: Welcome to Sonja McCartney who has been working with the support group team.

MovingUpTogether has a new facilitator – Laura Goring. This group is focusing on those who have early onset PD and are under 50 years of age.

Lansing Caregiver Support group thanks Dr. Jeanne Brown for organizing and facilitating this support group. Barb Hasbrook has now taken its helm.

We are sad to report that the following people have passed away. They were instrumental in facilitating support groups:



JUDITH E. FRITZ

Judy became involved in the Mt. Clemens Support Group (now disbanded) and graciously stepped in to facilitate it for four years, beginning in 2001, when the facilitator, Kay Tebo, stepped down. Judy, who had early onset Parkinson's, was determined that she and her family and friends would create a special place for the group, most of whom were much older than she. She knew what PD was about – her father had lived with PD for many years before. She was determined that everyone should understand what PD is and that support is available. Judy was vibrant, creative and brought beauty into everything she did.



BETTY RUSNACK

Betty was a highly regarded Professor of Social Work at Wayne State University for many years. A friend of hers who had PD, Ginny Downs, asked her to help her facilitate the Eastside Support Group in 1989, which Betty took on as a mission. When Ginny moved to Indiana, Betty remained, later to be joined by Jane Farrelly. Betty was a “quality person” and was over 90 years of age when she passed away. She continued her work with the Eastside group until the very end. She will be greatly missed, as she added a caring, professional, thoughtful approach to everyone she touched.



MERLE SMITH, PHD

The Rochester PD Support Group called Merle the “Dr. Phil” of the group. He presented several programs on depression and meditation. He had a marvelous sense of humor and made everyone he met feel comfortable in his presence. Quiet in nature, he was powerful in his volunteerism and caring for all who had the privilege of knowing him. His was a role model we would all hope to duplicate. (contributed by Nancy Knitter)

Merle was a clinical psychologist – a people person and an avid volunteer. I met him because my neurologist sent me to a psychological clinic in Rochester to discuss my health problems and he was the psychologist I saw. On one of my visits I told him I didn't have a ride to my next appointment. He volunteered

to rearrange his schedule to accommodate my appointment. He continued to help me to get to different places, including a Parkinson support group. When I wanted to start one in the Rochester area, he was also there to help. How lucky we were that he took enough interest in people with Parkinson's to help start the Rochester group.

Merle was a member of Civitans, a service club that raises money to support the handicapped – and he made sure that MPF was on this list. He was the head of the food pantry at his church, was a volunteer supervisor for psychologists at Eastwood Clinic and delivered leftovers from Panera Bread to the Baldwin Shelter in Pontiac. He would never hesitate to help someone in need. (contributed by Patricia Yarnold)



MI YOPD Support Group of Southeast MI

Educational Programs

LIVING WITH PARKINSON'S

Two Saturdays, Feb. 15 and 22, 2014,
from 9:30 am – 12:30 pm

Location: Hannan House
4750 Woodward, Detroit MI 48201

To pre-register, call 248-433-1011
No fee

These two sessions provide people with PD and family members with a more in depth view of what Parkinson's disease is and how it is managed. Speakers include prominent experts, including Dr. Edwin B. George, MD, PhD, Movement Disorder Specialist; Hazem A. Eltahawy, MD, Neurosurgeon; Dennis Parker, PharmD, Pharmacist; Richard Merson, PhD, speech and language pathologist; Jean Remilett, OTR, Occupational Therapist and more. There is limited seating, so you need to pre-register and attend both sessions.

ORIENTATION TO PARKINSON'S

Attend one 2 hour session that will provide you with an overview of what Parkinson's is for those who are newly diagnosed and their families. Presented by a nurse and a couple who have experienced PD for several years. No fee.

Mon: March 24, June 16, Oct. 6

Location: MPF offices 30400 Telegraph, Bingham Farms MI 48025

Tue: March 25, June 24, Oct. 7

Location: University Lutheran Church, 1020 South Harrison Road, East Lansing MI 48823

REGIONAL CONFERENCES

Last year's programs were very successful and we are planning several conferences beginning in April. Stay tuned for information.

**Grand Traverse
29th Annual Summer Forum**

Hold the date: Thursday, June 5, 2014



Timothy Collier, PhD
Director, Michigan State University Udall Center, Professor, Michigan State University College of Human Medicine, Department of Translational Science and Molecular Medicine. Member, Michigan Parkinson Foundation Professional Advisory Board.

An Argument for Early Intervention in PD

The recent report by Kordower and colleagues significantly adds to what we know about the time course of loss of the dopamine brain cells that are vulnerable to degeneration in Parkinson's disease (PD). The evidence provided by autopsy brain tissue from individuals who died at variable times after PD diagnosis indicates that the loss of dopamine neuron fibers in the brain structure putamen that are responsible for many of the movement disorders of PD occurs more rapidly than previously thought. Within 5 years of diagnosis 70-90% of dopamine fibers in putamen were lost. Interestingly, at this same time, 40-70% of the dopamine neuron cells in substantia nigra still remained.

The loss of the majority of dopamine neuron fibers that occurs over the course of the disease, but only becomes detectable by symptoms very late in the degeneration, underscores the critical need for biomarkers that identify at risk individuals early and permits early intervention with therapeutics to preserve the remaining fibers. The mismatch between stage of degeneration and recruitment of patients for clinical trials of experimental therapeutics, too late to be effective, may help explain the failure of trials for PD to date.

On a more positive note, the finding that many more dopamine neurons in the substantia nigra persist beyond the time when fibers are lost supports the hope that therapies that stimulate the surviving cells to re-grow their fibers may be effective in the treatment of PD.

Reference: Kordower JH, Olanow CW, Dodiya HB, Chu Y, Beach TG, Adler CH, Halliday GM, Bartus RT (2013) Disease duration and the integrity of the nigrostriatal system in Parkinson's disease. Brain 136:2419-2431.

Exercise Programs that are available in Michigan on a weekly basis that are specifically developed for people with Parkinson's include the following:

**Adaptive Exercise for Parkinson's with
Dr. Stuart Blatt, Physical Therapist (weekly)**

Ann Arbor, Detroit, Howell, Rochester (with support groups)

Hospital-based Programs

Bay Medical, Bay City

Beaumont Hospital Rehabilitation Center, Royal Oak

Bronson Hospital-Kalamazoo - Delay the Disease programs

St. John Hospital, Detroit

St. John Macomb Hospital, Warren

Pedaling for Parkinson's

Ann Arbor YMCA

Jackson YMCA

Generation Care, Muskegon

Tai Chi for Parkinson's

Traverse City Support Group

For LSVT BIG and other programs requiring a physician order, speak with your neurologist



How to Select an Exercise Program



The Michigan Parkinson Foundation's Professional Advisory Board and Board of Directors also published a position paper on the importance of exercise in the management of PD. Brian Cooper, OTR (Residential Home Health), Member of MPF's Professional Advisory Board wrote the following description of exercises that can help:

There are three main types of exercise to consider with Parkinson's: aerobic conditioning or cardiovascular exercise, strength or resistance training, and stretching or flexibility exercises.

An exercise program consisting of cardiovascular activities, stretching, strengthening, walking and balance training resulted in significant improvements in daily function and quality of life related to mobility and maintaining independence with activities of daily living.

AEROBIC OR CARDIOVASCULAR CONDITIONING:

Examples of aerobic or cardiovascular exercise include: walking (using trekking sticks), cycling, swimming, boxing, dancing, rowing, stair stepper or use of an elliptical machine.

STRENGTH TRAINING OR RESISTANCE TRAINING:

Examples of strength or resistance training include: lifting weights, completing exercises using body weight including squats, push-ups and lunges. When lifting weights, it is important to keep in mind that light weight can be more effective than using a heavy weight which could result in injury. Often 2 to 5 pound weights, when used appropriately, can be effective as well as using resistance bands.

STRETCHING:

Stretching programs should focus on postural deficits, improving trunk and head extension, pectoralis stretching to address rounded shoulders and improve lung functioning, hamstring stretches, and finger extension exercises. Activities incorporating stretching include yoga, pilates, and exercise programs geared toward fall prevention.

FALL PREVENTION/BALANCE EXERCISES:

There are many types of exercise programs that are geared toward fall prevention. One resource for fall prevention exercises are Sit and be Fit classes that can often be found on PBS. There are many books that are also dedicated to this subject. One comprehensive book is: *How to Prevent Falls: Better Balance, Independence and Energy in 6 Simple Steps* by Betty Perkins-Carpenter. Look for the program, *A Matter of Balance*, in your community. This program may be sponsored by your Area Agency on Aging or Commission on Aging

HOW TO GET INVOLVED WITH EXERCISES:

Group or community-based programs, local gyms or YMCAs, senior centers. You could contact a Physical or Occupational Therapist who specializes in neurological rehabilitation or has a



strong background in working with Parkinson's patients to get help in developing an exercise program that is safe and suitable to address your needs.

Find an exercise partner from a support group so that you can encourage one another to stay committed to an exercise program. Research has found that people are more inclined to adhere to their programs if they have a partner. This also helps with motivation.

INTENSITY:

As we are finding out, intensity is a valuable component of exercise. Movement only becomes exercise when it is done several times per week at an intensity that is high enough to be physically challenging. In other words, it may be necessary to break a sweat. Because Parkinson's is a disease of slowed movement, exercising at a slow rate may not provide the best results. Research shows that it is not the exercise, but the intensity which is most beneficial. This is where a therapist or an exercise partner may be beneficial to assist you in calibrating yourself to maintain a high intensity with your exercise.

DETERMINING AN EXERCISE PROGRAM THAT IS APPROPRIATE FOR YOU

It is important to take into consideration your physical capabilities when completing exercises. Often, it is necessary to start an exercise program in a sitting position due to balance deficits that can increase your risk for falls. As you progress, the exercises can be graded to be completed in a standing position.

Non-Profit Org.
U.S. Postage
PAID
Royal Oak, MI
Permit #108

MICHIGAN
Michigan Foundation
MESSENGER

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 55 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

Michigan Parkinson Foundation

PLEASE SEND INFORMATION ON:

- How I can become an exclusive member of the Michigan Parkinson Foundation's **CLUB 500**
 Parkinson's Disease

Enclosed is my gift of \$ _____

Visa Mastercard 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:

Name _____

Address _____

City _____ State _____ Zip _____

PLEASE CONTACT ME ABOUT:

- How I can make a Recurring Donation (weekly, monthly, etc.)
 How I might make a gift to MPF in my will, life, insurance or other special means which may have tax advantages.

My Name _____

Address _____

City _____ State _____ Zip _____

County _____

Phone _____

I want to receive further mailings:

By e-mail at _____

By regular mail

DO NOT SEND further mailings

DO NOT INCLUDE my name in publications

Your kind donation will be used wherever needed. Please make checks payable to: Michigan Parkinson Foundation.
All gifts are tax deductible as provided by law. Michigan Solicitation License #8287