



MESSENGER

Exciting things are happening in Michigan!

DON'T MISS THIS
EXCITING EVENING...



View MPF's newly
redesigned website at
www.parkinsonsmi.org

CONTENTS

Research in Michigan	1
Education Programs	10
Support Groups	11
Exercise & Movement Programs	12-13
Fund Raising for PD	14-15

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

Focusing on Parkinson's Research and Exercise Programs in Michigan

In this issue of the *Messenger*, we bring you highlights of some of the major Parkinson research programs in Michigan, describing the meaningful work in progress to find a cure and to improve treatment. This is not an all-inclusive list by any means, but it offers the reader an overview of the important involvement of several institutions and researchers within our midst.

We also wish to direct attention to the growth of programs to help people with Parkinson's stay healthy. Research studies have indicated that exercise and movement are beneficial to the quality of life and may even have a protective effect on disease progression. Michigan Parkinson Foundation's Professional Advisory Board has produced a Position Paper on the role of exercise in the management of PD (view on line at www.parkinsonsmi.org). The second section of this *Messenger* highlights examples of programs now available.

Raymond B. Bauer, MD, Research Award 2015

Evaluation of Two Neurofeedback Protocols with Parkinson Disease Patients



JoAnne McFarland
O'Rourke, LMSW

The Michigan Parkinson Foundation has had a restricted fund for research since 1983, named after our founding President, Raymond B. Bauer, M.D. The Professional Advisory Board selects from among applicants an investigator in Michigan, preferably working with students, who is studying an aspect of PD. In 2015, a 2-year grant for close to \$20,000 has been awarded to JoAnne McFarland O'Rourke, Director of Research, Western Michigan University College of Health and Human Services (CHHS) for her study.

A chief aim of the project funded by the award is to delineate treatment methods that address comorbid conditions that often accompany disease. For Parkinson's disease (PD), these issues involve physical health such as gait, balance, and fatigue; mental health, such as depression and anxiety; and cognition, such as memory, word-finding, and attention. These issues combine to affect virtually every aspect of life for PD sufferers. Moreover, it becomes difficult for patients and practitioners to sort out comorbidities, including which symptoms take priority and which may be contributing to others.

The award will fund a randomized controlled study evaluating two neurofeedback protocols. One protocol will address physical symptoms of PD while the other will target both physical and mental health aspects of the disease. Outcome measures will include physical and mental health assessments.

(cont. on page 8)

After half century of L-DOPA, new research offers improved therapies

Contributed by Peter A. LeWitt, M.D.



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; Presi-
dent, Michigan Parkinson
Foundation and Member,
MPF Professional Advisory
Board

With the arrival of L-DOPA (the active ingredient of Sinemet), living with PD for most persons changed for the better. This drug offered a rational way to control problems enacted by the loss of nerve cells in the PD brain. While L-DOPA is not a perfect therapy, it can bring most PD symptoms under control. However, as many patients have recognized, its actions can be inconsistent or sub-optimal, and side-effects can occur. L-DOPA is a short-acting medication needing pharmaceutical “tricks” to extend and control its benefits against PD. Fortunately, recent developments provided strong evidence for improved formulations.

Earlier this year, two new forms of L-DOPA gained approval by the Food and Drug Administration. One of them, **Duopa®**, contains L-DOPA in liquid form and is designed for continuous infusion into the upper small intestine. Extensively used in Europe, Duopa® can be quite helpful for controlling fluctuations in PD symptoms. However, it requires surgical installation of a small tube to deliver the drug by pump. Another form of L-DOPA recently marketed is an extended-release formulation, **Rytary®** (previously known as IPX066). Rytary®, which consists of tiny drug-bearing beads packed into capsules, aims to provide a longer and more consistent release of L-DOPA for better symptom control. With conventional forms of L-DOPA, benefits can be irregular and wearing-off can occur at intervals as short as 2-3 hours. Rytary® is quite useful for some patients but may require dose adjustment efforts to determine its proper dose. Its intent is to improve upon what generic carbidopa/L-DOPA (Sinemet) can provide - the ingredients are the same, the difference is in the slowed release of drug. However, this new formulation also adds expense, so that patients need to determine if its extra cost provides adequate value.

In the drug development sector, several other formulations of L-DOPA are being developed to achieve the same goal of more controlled drug delivery. The goal is to permit effective dosing at intervals longer than 4 hours between doses and to avoid peak effects like involuntary movements. These products will be investigated here in Michigan at the Henry Ford West Bloomfield Hospital PD research program, where a rapid-acting inhaled form of L-DOPA is currently being tested as a rescue for “off” episodes. Among ideas for constancy of L-DOPA effect is a pro-drug (that is, a form of L-DOPA linked to another substance to improve its uptake from the gastrointestinal tract). Completed studies with this product, **XP21279**, showed promise for achieving more consistent effects.

Two other L-DOPA slow-release formulations (one with research designation as **DM-1992** and the other named “**Accordion Pill**”) have had preliminary investigations that show considerable promise for more continuous delivery of L-DOPA than from conventional pill forms. Another treatment concept also in clinical testing involves giving a **solubilized form of L-DOPA** using a small portable pump that delivers the drug under the skin, much like the methods used to administer insulin for diabetes. This formulation also is planned for testing at the Henry Ford West Bloomfield Hospital.

Improved L-DOPA will require a lot of inventiveness and the help of patients to develop these products. Ideas for improving control of PD involve more than improve-

Research Projects For Parkinson's Disease At The University Of Michigan

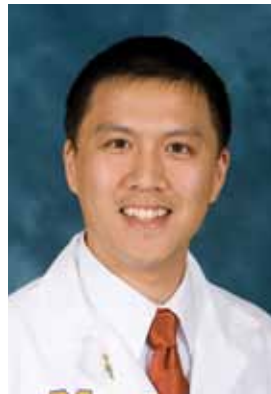
Contributed by Kelvin Chou, MD

ments in L-DOPA. Other current clinical investigations include ongoing trials of drugs known as “**adenosine A2a antagonists**”. Two members of this group, **istradefylline** and **tozadenant**, might lessen “off” time and other aspects of fluctuations in PD control. Another approach also undergoing testing in the Henry Ford Hospital West Bloomfield PD clinic is continuous infusion of **apomorphine**. This drug duplicates the effectiveness of L-DOPA and its continuous delivery is by a small pump injecting the drug under the skin. Apomorphine is also being tested for rapid “rescue” from an “off” state by placing it under the tongue. Each of these investigational approaches needs further testing to establish their safety and effectiveness. The variety of what is ahead for the PD community indicates clearly that this disorder has not been forgotten by researchers and the pharmaceutical industry.

Perhaps the most exciting developments are plans for several experimental approaches to slowing the progression of PD. These studies are planned for testing throughout the U.S., including here in Michigan. These projects, to be carried out collaboratively through the Parkinson Study Group and other consortia, may help us to learn how the threat of worsening in PD can be stopped.

An optimistic view of the future for PD is warranted – and worth sharing! It's not all about pills and other medication approaches, but, of course, these options add a lot to the picture of improved living with PD. For further information, contact Dawn Miller, RN or Patricia Kaminski C-NP at (248) 661-6540 or parkinsons@hfhs.org

NOTE: The Michigan Neurologic Institute is also a participant in the inhaled Levodopa trial, under Dr. Paul Cullis (Chief of Neurology, St John Providence Health, Associate Professor of Neurology, Wayne State University Board and PAB Member, Michigan Parkinson Foundation) Contact Bridget Patterson, RN, at 586-772-4080 for further information about participation in this study.



DR. KELVIN CHOU, M.D.,

Associate Professor, Depts. of Neurology and Neurosurgery, Thomas H. and Susan C. Brown Professor
Co-Director, Surgical Therapies Improving Movement (STIM) Program
Co-Director, Movement Disorders Clinic

DYNAMIC STANDING

The University of Michigan and VA Ann Arbor Medical Center were recently awarded a grant to study “dynamic standing” as a novel means of non-exercise physical activity in PD. Due to movement and balance problems, PD patients may favor a sitting, or sedentary lifestyle; physical inactivity, in turn, results in a downward spiral of movement problems. Ongoing physical fitness should be strongly recommended to PD patients who are at risk of physical deconditioning, balance problems, and a fear of falling. There have been recent initiatives to “Stand Up, Sit Less, and Move More” in the PD community. Investigators at the Uni-

versity of Michigan have developed a novel way of standing (“dynamic standing”) that enhances standing by promoting continuous weight-shifting movements. In this project, persons with PD will participate in 12 half-day sessions that will involve routine desktop physical activities such as computer use, watching movies, reading, or playing games.

For more background information on these studies you can call the University of Michigan Functional Neuroimaging, Cognitive and Mobility Laboratory at 1-877-998-1098.

STEADY-PD III

The University of Michigan is also one of the sites for the STEADY-PDIII study. This study, sponsored by the National Institutes of Neurological Diseases and Stroke (NINDS) and conducted through the Parkinson Study Group (PSG), is designed to determine the effectiveness of isradipine on slowing the progression of Parkinson disease. Isradipine is a medication that is approved for the treatment of high blood pressure by the Food and Drug Administration (FDA), but not for the treatment of PD. In order to participate, subjects cannot be taking dopaminergic medications for PD.

For more information on participating in this study, you can contact Jamie Miller at the University of Michigan 734-936-4817.

Brains in the balance: New \$11.5M grant fuels U-M Parkinson's disease research center to aid patients

New U-M Center Focuses on Gait and Balance Problems in Parkinson's

Contributed by Roger Albin, MD



ROGER L. ALBIN, MD

Anne B. Young Collegiate Professor of Neurology, University of Michigan Medical School
Chief, Neuroscience Research, VAAHS GRECC,
Past member, MPF PAB

Deep in the brains of the million Americans with Parkinson's disease, something has gone terribly wrong. And it keeps getting worse, even with the most modern treatments, eventually robbing patients of their ability to walk. Now, University of Michigan scientists and doctors have launched a five-year, \$11.5 million effort to study why this happens, and find new options based on the latest brain science. Much of the work is clinical research on patients with earlier stages of Parkinson's before falls emerge, but it is hoped that the novel therapeutic approach will ultimately help decrease falls in those experiencing them. Involvement of adequate numbers of patients is critical for success (those interested in participating can register to be contacted as described at the end of the article).

The new research focuses on a brain chemical system that is rapidly emerging as a key player in the disease's effect on walking and balance – in large part due to advances made at U-M. That system, which helps us focus our attention on tasks such as walking, may be the next key target for new Parkinson's treatments. With the new grant from the National Institute of Neurological Diseases and Stroke, part of the National Institutes of Health, U-M becomes home to one of only 9 Morris K. Udall Centers of Excellence in Parkinson's Disease Research in the country. Named for a noted member of Congress who battled the disease, the centers bring together researchers from many fields to tackle big questions in Parkinson's, to educate the next generation of Parkinson's researchers, and to serve as a vital resource for patients with the disease. The U-M Udall Center team came together

from many areas of the university. They include Medical School doctors who treat Parkinson's patients at the U-M Health System and the VA Ann Arbor Healthcare System, and study the disease in their labs, as well as a psychologist in the College of Literature, Science & the Arts, and faculty from the schools of Nursing and Public Health.

They'll focus mainly on the brain's cholinergic system: groups of brain cells that talk to one another via the chemical acetylcholine, and govern our ability to pay attention. "Understanding the role of the cholinergic system is a key unexplored frontier in Parkinson's disease, and will allow us to go beyond the limits of current practice, so we can create better therapies to suppress the terrible symptoms of the disease that affect balance, walking and overall independence," says William Dauer, M.D., who will be the center's director. Dauer directs the UMHS Movement Disorders program and is the Elinor Levine Professor of Neurology, and an Associate professor of Cell and Molecular Biology, in the U-M Medical School.

Targeting the "Double Whammy" of Parkinson's Brain Cell Loss

Most Parkinson's disease research and treatment focuses on the brain's dopamine system, which normally helps control movement. This control breaks down in Parkinson's patients, as more and more dopamine-producing brain cells called neurons die -- a process called neurodegeneration. Medicines to replace lost dopamine help correct the slowness, stiffness and tremor typical of the disease, but over time patients lose the ability to walk or even stand safely – symptoms that are resistant to dopamine therapy. They become prone to serious falls, which can lead to disastrous medical and social consequences.



Pioneering work on patients with Parkinson's by U-M brain imaging researcher Nicolaas Bohnen, M.D., Ph.D., a Professor of Radiology and Neurology, suggests that the spread of neurodegeneration to the cells of the cholinergic system creates a “double whammy” effect. That is, it robs the patient of the ability to pay close attention to their movements even as they're already having trouble walking safely. The involvement of the cholinergic system likely explains why current treatments – focused on dopamine replacement – make these symptoms resistant to treatment.

The new center will conduct three interrelated projects to better understand the role of the cholinergic system in falls, focusing on the effect of lost cholinergic neurons in brain areas called the basal forebrain, which regulates attention, and the pedunculopontine nucleus, or PPN, which controls balance. In both rats and people, the team will work to study this effect, and to determine if it's possible to increase cholinergic traffic in the brains of patients using an already-approved drug that targets acetylcholine receptors on the surface of brain cells. That drug, varenicline or Chantix, is already available by prescription to help people stop smoking.

Neurologist Roger Albin, M.D., will serve as the center's Associate Director, and co-lead with Dauer a project to develop “personalized medicine” approaches to Parkinson's disease using specialized brain scanning and varenicline. They'll measure whether the drug has an effect on walking ability. They'll use a method – developed by Bohnen, Albin and colleagues – that makes it possible to see cholinergic activity with greater detail than ever before possible, using positron emission tomography, or PET, scanning. Albin, an internationally known Parkinson's researcher, is the Anne B. Young Collegiate Professor of Neurology at U-M and leads neuroscience research at the VA Ann Arbor Healthcare System's Geriatrics Research, Education and Clinical Center.

Another key leader of the center is U-M neuroscientist Martin Sarter, Ph.D., the Charles M. Butter Collegiate Professor of Psychology in the College of Literature, Science & the Arts and a professor in U-M's Neuroscience Program. He is a world leader in research on the cholinergic system. In groundbreaking work, Sarter and his team have already shown in rats that the cholinergic system plays a key role in balance and walking, and that reduced cholinergic activity is associated with worse balance and more falls. They'll continue to explore this issue, and the role of the PPN brain area, in their animal model even as the work in humans continues.

A team of biostatisticians and data management specialists led by Ivaylo Dinov, Ph.D., of the U-M School of Nursing, and Cathie Spino, D.Sc., of the U-M School of Public Health, will help design and analyze the results of the center's experiments, using advanced digital tools to parse the massive amounts of data the work will produce. An education and outreach effort will be led by Kelvin Chou, M.D., co-director of U-M's Surgical Therapies Improving Movement (STIM) deep brain stimulation program for Parkinson's disease. Dr. Chou will work to educate caregivers about Parkinson's disease management, and especially the issue of falls. He is the Thomas H. and Susan C. Brown Early Career Professor in the Department of Neurology, and an associate professor in the Department of Neurosurgery. The center will also partner with the Michigan Alzheimer's Disease Center in minority outreach efforts, and run a Udall Center Fellows program, co-funded by U-M Medical School and the Department of Neurology, which will allow physicians and physician-scientists interested in Parkinson's disease to receive two years of intensive training and participate in center research.

Research Participation

Interested PD patients can indicate an interest in participation via the University of Michigan Clinical Research website; www.umclinicalstudies.org. Search for “Parkinson's disease” and click on a study titled “Cholinergic Mechanisms of Gait Dysfunction in Parkinson's Disease.” Alternatively, call clinical research coordinators Christine Minderovic (734-998-8400) or Jamie Miller (734-936-4817) and say that you're interested in the Udall study.



TIMOTHY COLLIER, Ph.D.
 Director, Michigan State University Udall Center; Professor, Michigan State University College of Human Medicine, Dept. of Translational Science & Molecular Medicine; Edwin A. Brophy Endowed Chair in Central Nervous System Disorders; Member, Michigan Parkinson Foundation Professional Advisory Board

Slowing Parkinson's Progression, Grand Rapids

Contributed by Timothy Collier, Ph.D.

For most individuals diagnosed with Parkinson's disease, managing their symptoms is an ever-changing challenge as old symptoms become a little worse, and new symptoms emerge. While best medical therapy and lifestyle can provide good benefits early, adequate treatment becomes complicated and incomplete as time passes. While scientists worldwide continue to work toward a cure for Parkinson's, a more immediate goal is to slow progression of the disease, keeping symptoms in the "sweet spot" that can be managed relatively well with existing therapies.

Ongoing research at MSU-Grand Rapids covers a wide range of topics, including deep brain stimulation, gene therapy, preventing/treating dyskinesias, inflammation, repurposing drugs, and the role of aging. Here I highlight two studies directed at predicting the progression of Parkinson's and one approach to slowing down the clock.

A study directed by Dr. Caryl Sortwell focuses on a common genetic variation in the population that appears to predict both the likely rate of progression of the disease, and inform individuals about the potential value of treatments for Parkinson's. One brain chemical that has been identified as critical to the health of the dopamine neurons vulnerable in Parkinson's is brain-derived neurotrophic factor (BDNF). A small variation in the specific structure of the BDNF gene, present in about 35% of the population, changes how much BDNF is accessible to the brain. The accumulating evidence from Dr. Sortwell's study indicates that the presence of this genetic variation can be useful in anticipating how rapidly Parkinson's symptoms may change in a given individual, and what treatment approach may be most beneficial. The genetic difference is readily detected from a sample of saliva, and may be useful to patient and physician in planning patient-specific management of symptoms.

A second study directed by Dr. Katrina Paumier and Dr. Tim Collier focuses on an unexpected action of a drug with a long history of use as a treatment for depression. The drug, nortriptyline, is no longer the first choice for treatment of depression as more specific drugs with fewer side effects were developed over the years. However, these more specific drugs lose some of their utility when the goal is to use them for Parkinson's: a complex drug to treat a complex disease. The unexpected action of nortriptyline is its ability to slow the accumulation and clumping of alpha-synuclein, a protein linked to dopamine neuron degeneration in Parkinson's. If the action of this drug translates from our laboratory studies to the clinic, it may be useful in slowing progression of symptoms in individuals with Parkinson's, preserving that therapeutic "sweet spot" for managing the disease.

For further information, please contact Dr. Collier at timothy.collier@hc.msu.edu.



**JOHN L. GOODREAU,
D.O., PH.D**

Associate Professor,
Department of Neurology and Ophthalmology and Department of Pharmacology and Toxicology, Michigan State University School of Human Medicine and School of Osteopathic Medicine, Director, Translational Neurobiology Research Unit; Director, Movement Disorders Clinic; MPF Professional Advisory Board Member

Research at the Movement Disorders Clinic, East Lansing

Contributed by John L. Goudreau, D.O., Ph.D.

The Movement Disorders Clinic in the Department of Neurology at Michigan State University continues active research in the following areas related to Parkinson disease (PD).

CLINICAL TRIALS TO FIND DRUGS THAT SLOW DISEASE PROGRESSION

The STEADY-PD3 study is enrolling PD participants who have not yet started symptomatic medications and will test the disease-modifying effects of isradipine, a calcium channel blocking drug currently used to treat high blood pressure. The SURE-PD study starting in 2016, will evaluate the disease modifying effects of a drug, inosine, that can normalize uric acid levels in PD participants who have abnormally low uric acid levels (this group of PD patients appears to have a faster rate of progression than those with normal uric acid levels).

CLINICAL TRIALS OF DRUGS THAT TREAT PD SYMPTOMS OR COMPLICATIONS

A phase III trial of tozadenant is recruiting PD participants who take Sinemet (carbidopa/levodopa) more than 4 times per day and continue to have bothersome wearing off benefit. The MOVE-PD study recently concluded enrollment and is focused on an injectable drug to alleviate chronic constipation in people with PD.

BIOMARKERS OF PD SUBTYPES

Dr. Goudreau is collaborating with Dr. Sortwell from the MSU Udall Center in Grand Rapids to develop a gene test that could aid in the decision of when to consider using deep brain stimulation (DBS) therapy versus continuing to use medications alone to manage PD motor symptoms. Future clinical trials, in collaboration with Vanderbilt University, may examine the value of very early introduction of DBS in the treatment of PD.

ASSESSMENT AND UNDERSTANDING OF SYMPTOMS

Dr. Goudreau has completed a collaboration with Dr. Rahul Shrivastav on technology to evaluate early and progressive speech changes in PD. Work with Dr. Susan Ravizza continues to examine how memory processing occurs in normal aging and in people with PD. Initial studies are being conducted with Dr. Dan Morris, Department of Engineering, to evaluate the utility of next generation X-Box Kinect™ sensor technology to remotely assess PD symptoms.

THERAPY TARGET IDENTIFICATION AND VALIDATION

Dr. Goudreau’s basic and translation research lab continues to leverage studies of a unique group of dopamine neurons that appear to resist degeneration in PD. Parkin and UCHL-1 are proteins that allow these nerve cells (neurons) to recover from an injury that would normally kill the dopamine cells that die in PD. Therapy targets can be evaluated by finding out how the cells that recover can rapidly increase the level of protective proteins (like Parkin and UCHL-1) and how these protective proteins allow the cell to recover.

For further information on Michigan State University East Lansing programs, call (517) 884-2274.

Contributed by Dr. Edwin B. George,
M.D., Ph.D.



EDWIN GEORGE, M.D., PH.D.
Assistant Professor of Neurology, Wayne State University School of Medicine, Director of Movement disorders Center, Wayne State University and the John D. Dingell Veterans Administration Hospital; Chairman, MPF Board of Directors, Member and past Chairman, MPF Professional Advisory Board.

The Wayne State University Movement Disorders Center and the Sastry Advanced Imaging Laboratory continue to recruit patients to participate in our study of optical coherence tomography (OCT) in Parkinson's disease. This quick and painless non-invasive technique captures an image of the retina in the back of the eye, which is used to assess the progression of Parkinson's disease. The initial phase of the study is currently in publication with the *Journal of the Neurological Sciences*, but the second phase of the study continues to recruit patients.

The study of MRI spectroscopy to assess the changes in the substantia nigra in Parkinson's disease has been completed and will appear shortly in *Movement*

Disorders. Recruitment of patients for a study on visual processing in Parkinson's disease and its role in hallucinations is expected to begin this fall. This study will include MRI and a computerized assessment of visual perception in Parkinson's disease patients. For further information, contact the Neurology clinic at (313)745-4275

Quest Research Institute



QUEST
RESEARCH
INSTITUTE

Contributed by Dolly Niles,
Executive Director



Quest Research, located in Bingham Farms, has been active for many years in conducting clinical studies related to Parkinson's disease. Several trials are being held that examine the treatment of relevant symptoms, such as "wearing off" and dyskinesia. Two investigational medications are being studied which are to be used in between regular doses of current Sinemet or Rytary, if one is experiencing wearing off. These are in an inhaled form (like asthma medication) or a sublingual strip (like the popular breath freshener). The hope is that this method of delivering medication will help someone who is "off" become "on" quickly.

Dyskinesias are experienced when daily Sinemet causes a peak-dose period of unwanted movements (writhing, wiggling). One investigational treatment needs to insure that it is safe prior to being placed on the market.

Another agonist medication that would be administered once a day is being studied. This requires being at Quest for 24 days! During the 24-day period, the trial participant slowly increases the study medication and decreases their Sinemet until they are completely off Sinemet, being evaluated throughout.

Quest is also involved in research trials of a drug thought to help reduce alpha synuclein in the brain.

Finally, Quest is testing out smartphones and corresponding "apps" to measure a person's Parkinson's symptoms through the day. This could assist in providing accurate information to the treating doctor to allow for fine-tuning medication.

For further information, contact Quest at www.questri.com or 888-QUEST-24.

Raymond B. Bauer, MD, Research Award 2015

Evaluation of Two Neurofeedback Protocols with Parkinson Disease Patients (cont. from page 1)

Neurofeedback (NFB) is a human-computer interface designed to regulate and thereby optimize brain function. A number of studies have demonstrated the effectiveness of neurofeedback for different issues, including Attention Deficit Disorder/Hyperactivity (ADD/ADHD), migraine, and depression. A smaller number of studies have shown positive results on degenerative diseases, including PD and Alzheimer's.

According to Ms. McFarland O'Rourke, research has shown that the later a person is diagnosed with PD, as well as the comorbid presence of dementia and psychosis, the more quickly the disease progresses. The gradually progressive nature of PD, combined with the multiple facets of life affected by the disease, as well as the benefit of early diagnosis and treatment, create an urgent need for finding ways to alleviate and delay symptoms for as long as possible. She is hopeful that the new study will help address the comprehensive nature of PD and lead to more effective, holistic approaches to treatment, in addition to delineating symptoms that can best be addressed without medication.

For those interested in becoming a part of this study, Ms. O'Rourke can be contacted at (269) 387-8445 or joanne.orourke@wmich.edu



Van Andel
Institute®

Parkinson's disease research at Van Andel Research Institute, Grand Rapids MI

Van Andel Research Institute (VARI) is an independent biomedical research organization committed to improving the health and enhancing the lives of current and future generations. VARI's Center for Neurodegenerative Science focuses on the development of novel treatments that slow or stop the progression of neurodegenerative diseases, in particular Parkinson's disease. The Center's work revolves around three main goals: disease modification, biomarker discovery, and brain repair.



Patrik Brundin,
M.D., Ph.D.

Director, Center for
Neurodegenerative
Science and
Associate Research
Director, Van Andel
Research Institute;
Adjunct Professor,
MSU College of
Human Medicine

THE CENTER'S FIVE LABORATORIES EACH FOCUS ON A SPECIALIZED AREA OF PARKINSON'S DISEASE RESEARCH

- Center Director Dr. Patrik Brundin's laboratory studies cellular mechanisms of Parkinson's. The lab focuses on an aberrant form of protein called alpha-synuclein, which is the major constituent of abnormal protein clumps called Lewy bodies that are found in the brains of people with Parkinson's. Dr. Brundin's team is mapping how alpha-synuclein is involved in the spread of Parkinson's through the brain. In addition, they focus on novel therapeutic targets related to inflammation and cellular energy deficits.
- Dr. Jiyan Ma's lab studies abnormally folded proteins in age-related neurodegenerative disorders, like Parkinson's. By better understanding how errors in protein folding occur and how clumps of these abnormal proteins are linked to neurodegeneration, Dr. Ma's team hopes to develop new preventive therapies.
- Dr. Darren Moore's laboratory takes a different approach by studying the genetic causes of Parkinson's disease. Although most Parkinson's cases occur sporadically, about five to 10 percent are inherited genetically. By studying the products of genes associated with inherited Parkinson's, Moore's team hopes to discover new approaches for slowing or stopping disease progression.
- Dr. Lena Brundin studies how inflammation and the chemicals involved in inflammatory responses can give rise to psychiatric symptoms, such as depression and fatigue—common non-motor symptoms of Parkinson's. The ultimate goal of her work is to find new therapeutic strategies that target inflammation to improve treatment outcomes for depression and suicidal tendencies.
- Understanding the process of normal aging and its impact on the development of neurodegenerative conditions is a vital component to developing new treatments. Dr. Jeremy Van Raamsdonk and his team seek to unravel the mechanisms behind cellular aging and how these changes can contribute to neurodegenerative disease in order to develop novel strategies for preventing nerve cell degeneration.

Global collaborations

The Institute is committed to streamlining the route between laboratory and the clinic through its participation in the Linked Clinical Trials (LCT) initiative, a joint global initiative established by United Kingdom-based research charity The Cure Parkinson's Trust. The LCT Scientific Committee is chaired by Dr. Patrik Brundin, and evaluates medications approved to treat other diseases to explore if they can be repurposed as drugs that slow progression of Parkinson's. This approach can dramatically cut the time and cost required to develop a new medication that uniquely modifies the course of the disease.

Most recently, the Institute signed a letter of understanding with the Netherlands-based ParkinsonNet that lays the foundation for making Grand Rapids the epicenter for ParkinsonNet's expansion in West Michigan. Based at Radboud University Medical Centre, ParkinsonNet provides patients across the Netherlands with increased access to Parkinson's experts, making it easier for patients to get the expert care they need. Currently, ParkinsonNet connects more than 3,000 medical and health professionals in the Netherlands with people with Parkinson's who may have difficulty accessing specialized care.

For information, contact Patrick Placzkowski at (616)234-5030.

Traverse City Summer Forum

The 30th Annual Traverse City Summer Forum, organized by the Parkinson Network North on June 4 was a tremendous success. The theme, *Stand Up, Sit Less, & Move More*, was thoroughly covered in an inspiring keynote talk by Dr. Nicolaas Bohnen, from the University of Michigan and Ann Arbor VA Movement Disorders Clinic, who presented results of recent research studies.



Dr. Nicolaas
Bohnen



Maxine Meach

Dr. Bohnen discussed that balance and gait difficulties in PD – which are generally the least responsive to dopaminergic therapy - incline many patients towards a sedentary lifestyle with increased risk for the negative consequences of physical inactivity. A vicious cycle of worsening parkinsonism and increasingly sedentary behavior may explain decreasing physical activity in advanced PD. He presented data that regardless of the sever-

ity of PD, in terms of loss of dopaminergic brain cells, engagement in physical activities may improve motor symptoms in PD. More importantly, he emphasized that routine activities of daily living, like doing household chores, working in the garden, and any activities that avoid sitting, may be as important as more vigorous exercise activities. He concluded that these data add to an emerging body of literature in exercise physiology that both inactivity and vigorous exercise appear to have independent effects on health outcomes and that “Stand-Up, Sit-Less, Move-More” intervention strategies should be promoted for persons with PD.

The packed house also honored Maxine Meach for her 30 years of inspirational leadership. She received a proclamation from the city, a front page write up in the *Traverse City Record Eagle*, and a decorative crystal from Michigan Parkinson Foundation.

EDUCATIONAL PROGRAMS

Please go on line to our website to view upcoming education programs:
www.parkinsonsonsmi.org/programs-support-groups/educational-programs.

Call the MPF office to register, as space is limited: (248) 433-1011.

The **LIVING WITH PARKINSON'S** series (5-6 weeks) will be held in Frankenmuth, Flint and Lansing.

BEYOND THE BASICS: a series for those with early onset Parkinson's and family members (6 week series) will be held in the Metro Detroit area. Date to be determined.

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

Care Partner 2-part Seminar: A Pilot Program:

November 7 and 21, from 9:30 am – 12:30 pm

The two-session series for family care partners—spouses, children, parents— which will cover different aspects of the caregiving experience, including: caregiver stress, coping strategies, area resources, legal issues and planning for the future. These sessions will be facilitated by Nancy Knitter, Rochester Support Group Facilitator, Board Member and Care Partner, with guest speakers. Pre-registration is mandatory, as space is limited. Call MPF at (248)433-1011.

People with Parkinson's whose family member attends this program are welcome to participate in a separate session at the same time.

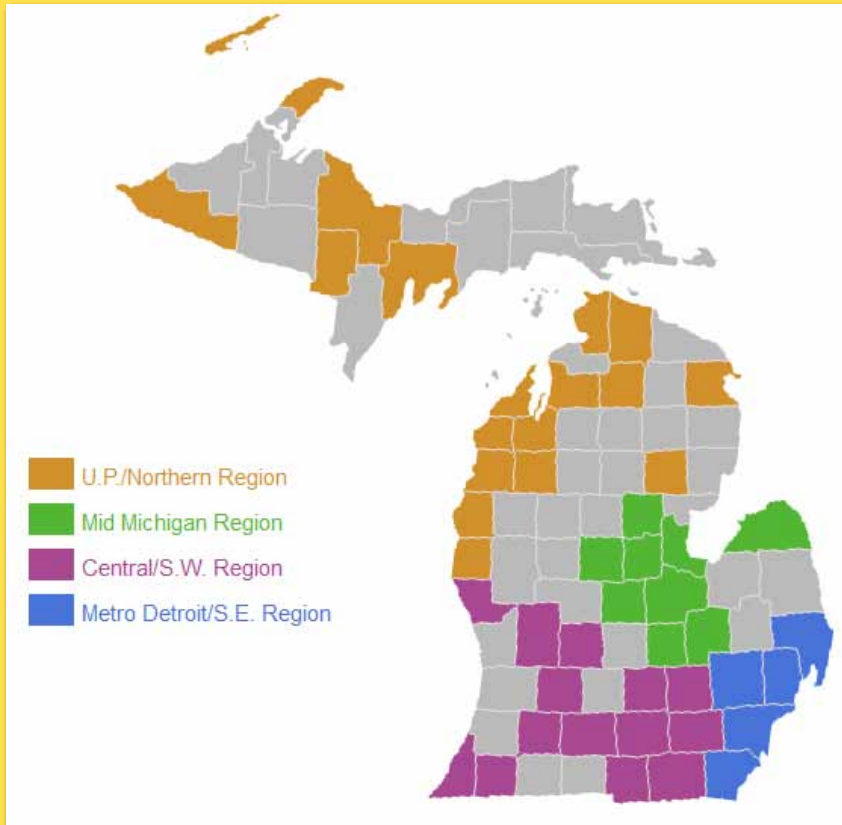
Location: Crittenton Hospital Auditorium,
1101 W. University, Rochester Hills, MI 48307.

SAVE the DATE: Friday, October 30, 2015

University of Michigan's STIM Program will present its Annual Symposium: **Parkinson's Disease & You.** Registration opens October 1, 2015. Contact Laura Zeitlin for further information at 734-998-9350. Details to follow.

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
Bay County
Berrien County (St. Joseph)
Cadillac
Calumet
Cass County/Cassopolis
Cheboygan

Dearborn
Detroit
Dickinson County Area
Downriver
Escanaba
Flint
Frankenmuth
Frankfort
Gaylord (OCCOA-Gaylord)
Gladwin
Grand Rapids – Hauenstein Center

Grand Traverse - Evening Group
Gratiot County
Grosse Pointe Farms
Hillsdale
Howell
Ionia
Ironwood
Jackson
Kalamazoo
Lansing Caregivers' / Dialog Groups
Lansing/East Lansing
Leelanau
Lenawee County (Adrian)
Livonia (Western Wayne)
Manistee
Mason County (Scottville)
Midland
Mid Michigan Young Onset
Montcalm County
MovingUpTogether
Mt. Pleasant (CMU)
Muskegon: Parkinson's Power
Muskegon Caregivers
Negaunee/Marquette County
Novi/Fox Run
Owosso
Parkinson Network North (Traverse City)
Petoskey
Port Huron
Rochester
Royal Oak/South Oakland
Thumb Area (Bad Axe)
Tri-City/Saginaw
Warren
West Bloomfield
West Branch
Young Onset Of Southeast Michigan



In recent years increasing attention is being focused on the role of exercise in the management of Parkinson's disease in delaying or reversing functional decline. Exercise is defined as "a planned, structured physical activity which aims to improve one or more aspects of physical fitness." (Morris M, Schoo, A. *Optimizing Exercise And Physical Activity In Older Adults*. Edinburgh: Butterworth Heinemann Publisher, 2004). There are many forms of exercise programs which can be of benefit to those with Parkinson's disease, and exercise can be performed on one's own or with a group. However, developing an exercise habit can be crucial to the outcome and can be difficult for many people to accomplish. Organized programs can be of benefit for many people.

MPF is collecting information about the type and location of exercise programs available throughout the state that have been demonstrated to be targeted to people with PD, have high standards and which are conducted by trained instructors. There are additionally programs available which require a physician's order and are considered a therapy rather than an exercise program, which can be identified elsewhere.

A listing of exercise and movement programs and how to connect with them can be found on MPF's website, <http://www.parkinsonsmi.org/programs-support-groups/exercise-movement-activities>. Here are some examples:

HOSPITAL BASED PROGRAMS include those at St. John Macomb Hospital in Warren, St. John Hospital Detroit, Bay Medical in Bay City, Hauenstein Center at Mercy Health- St. Mary's in Grand Rapids, Genesys Hospital in Flint, and Metro Health Hospital in Byron Center.

St. John Macomb's group exercise class, started over 27 years ago, is a chair-based strength and range of motion (ROM) program with components of stretching, breathing and voice exercises. They incorporate BIG movements and utilize other equipment, such as therabands, balls, balloons, parachute, and ROM sticks. Music is played to keep it going and interesting. The class meets Thursdays between 4 and 5 pm with 2-3 Rehabilitation staff.

The Parkinson's Exercise and Recreation Class (PERC) is part of the multidisciplinary approach of the Parkinson's and Movement disorders program of the Hauenstein Neurosciences at Mercy Health Saint Mary's,

Grand Rapids. The class meets twice a week and emphasizes exercises to offset changes prominent in PD: stiffness, weakness, posture and balance restrictions. Led by physical therapists with experience in Parkinson's management, activities performed in sitting and standing provide stimulation to help keep mobility skills safe.

PROGRAMS DEVELOPED BY PHYSICAL THERAPISTS

Dr. Stuart Blatt, who is on MPF's Professional Advisory Board, has been conducting weekly "Adaptive Exercise Programs" in conjunction with several support groups: Howell, Rochester, Ann Arbor and West Bloomfield. His focus is on building a strong body and spirit through camaraderie in an effort to combat the symptoms associated with Parkinson's disease. The exercises focus on core stability, balance and weight shifting to improve safety and reduce falls of the participants. At the beginning and at set times during the year, participants will be videotaped to see their progress. Stuart has been donating his time for several years to conduct these programs.

DELAY THE DISEASE PROGRAMS

First developed in Ohio by David Zid, the classes are being held in several Michigan locations.

In Kalamazoo, Bronson Lifestyle Improvement Center, the classes are divided into 3 groups based largely on fall risk and meet twice weekly for one hour. The instructors must be certified and have an understanding of Parkinson's disease. The instructors are able to modify the exercises based on the individuals within the class, and include exercises for strength, endurance and balance with many different levels based on ability of participants. They also add use of exercise bikes and occasionally dance to the routine to help keep interest levels high.

The YMCAs in Farmington Hills and Macomb have recently started Delay the Disease programs for the Parkinson community.

PEDALING FOR PARKINSON'S is being presented at Generation Care (Muskegon) and at the YMCAs in Ann Arbor, Jackson and Negaunee. Generation Care's version is the following:

Using a tandem bike, with the client with PD in the front seat, this program is supported by volunteer riders who push the revolutions to hit key targets of speed and duration. Following Cleveland clinic's protocol of 3 times



a week, 40 minute sessions at 80 rpm's, pedaling is a way to engage others in exercise programming. This is often described as an "I-feel-more-like-myself" type of exercise experience.

In addition, Generation Care has several other exercise programs for people with PD including aquatics, "Go Group" and Tai Chi.

DANCING TO COMBAT PARKINSON'S

"We Swing to Sinatra, sway with Ella, rock to Elvis and bounce to Broadway! It is a fun packed hour with lots of laughter. A great addition to your exercise routine."

...Terrye Mock

Programs involving dance for people with PD have been growing in popularity. Professional dancers have attended special training programs offered by the Mark Morris Dance Company from New York. In Dance for Parkinson's classes, participants are empowered to explore movement and music in ways that are refreshing, enjoyable, stimulating and creative. Active demonstration by professional dancers inspires participants to recapture grace, while guided improvisation fosters creativity, and experimentation with movement.

Current locations of these dance programs are:

- Oakland University, hosted by Take Root, led by professor Ali Woerner (takerootdance@gmail.com)
- Bloomfield Township Senior Center and Christina's Adult Ballet and More (Farmington Hills), led by dancer Terrye Mock (248-505-2951)
- Turner Senior Resource Center at University of Michigan (lzeitlan@med.umich.edu)



"This past weekend was truly one of the best experiences I have ever had as a dancer. Having toured the world as a professional and danced in beautiful theaters and venues, THIS experience tops all of it! I am so fortunate to be in this position, to pass on what I know to this special and unique group of people. I took a quiet moment in my office once everyone had left and just sat. I wanted to absorb all of it and be present in the emotions. There is a definite need for this kind of class, and I can't thank you enough for your support!... Ali Woerner

A UNIQUE OPPORTUNITY IN LANSING

Making the Turn Against Parkinson's, created by Todd Gardner of Williamston, partnered with the Michigan Athletic Club (MAC) in East Lansing, MI this past June, to offer a 12-week exercise therapy program designed specifically for Parkinson's patients. The program focuses on strengthening leg and core muscles to provide patients with better balance and gait promoting fewer falls and injury.

While all participants benefit, a number of participants experienced remarkable measurable improvements in their overall health in a short period of time. One person saw their rating on the Unified Parkinson's scale drop from 25 to 18 in just 6 weeks! (scale is 1-35, the lower the number the better). Due to the success of the 12-week program, the MAC is now offering the Parkinson's exercise therapy program on an ongoing basis free of charge, thanks to a subsidy from *Making the Turn*.

INNOVATIVE PROGRAMS USING OTHER MOVEMENT FORMATS

For a few years, Hettie Molvang, Facilitator of Traverse City's Parkinson Network North, has held dance and Tai Chi classes on a regular basis. Most recently we have heard from Mike Demeter, Senior Instructor, PD Fitness for Life, who has Young Onset PD and has organized Martial Arts classes for people with PD in Troy and Livonia in the Metro Detroit area.

Again, research is pointing to the importance of movement and activity to the optimal health of those with Parkinson's (and their families). You can review the Position Paper on Exercise which has useful guidelines for the person with PD, the health provider, and professional conducting exercise programs: <http://parkinsonsmi.org/managing-pd-special-documents?view=entry&id=45> or call MPF for a copy.

Again, please view MPF's website for details and contact information: <http://parkinsonsmi.org/programs-support-groups/exercise-movement-activities>

We are grateful for the help of the following:

Lansing Area:

Host - Okemos High School
special thanks to Ken Green

Emcee: Cheryl Fritze,
of WLNS TV

Pledge of Allegiance:
Isa Rodriguez, Someko Singer

Pushup For Parkinson's:
Michelle's Studio of Dance

Media Sponsors:

WILX TV, HOM and CAM TV

Sponsors:

Presenting - Anonymous

Gold Sponsor:

Lundbeck, UCB
US World Meds

Silver Sponsors:

Sparrow Health System
Capital Honda
Great Lakes Caring
Medtronics, TEVA

Bronze Sponsors:

MSU Dept. of Neurology
Alice & Roy Erickson
McLaren Greater Lansing

Friends Sponsors:

Warmels and Comstock
Dawn Feldpausch & Family in
memory of Alice M. Spitzley
Shaheen Chevrolet
Peak Performance

In-Kind Donors

Biggby Coffee
Creative Wellness (massage)
Great Lakes Caring
Home Depot
Meijer (Okemos)
Michigan Community VNA
Panera Bread
Playmakers
Residential Home Health

Committee:

Jim Galloway, Chairman
Brian Cooper, Run Chair
Jim Jablonski,
Music and Sound Chair

I Gave My Sole for Parkinsons

On August 8 and 9, Michigan Parkinson Foundation held its annual *I Gave My Sole for Parkinson's* Walk-a-thons in Okemos (with a 5K Run) and in Kalamazoo, thanks to the tremendous cooperation and help of the Lansing Area and Kalamazoo Area Parkinson Support Groups. More than 400 people attended both events, raising over \$41,000 in Okemos and more than \$9,000 in Kalamazoo.



Dr. Jeanne Brown
Suzy Hunter
Rose Mary Hubbert
Michelle McDevitt
Denise Van Effen RN, MSU
Joyce Wagner
Diane Kraft, staff

Honorary Chairs:

Michelle McDevitt
State Sen. Rick Jones,
24th District;
Frank Walsh
Meridian Twp Manager

Special Thanks to volunteers

Troop 164 from Okemos

Kalamazoo Area:

Celery Flats Historical Area,
Portage Michigan

Gold Sponsors:

Lundbeck
TEVA
UCB
US World Meds

Sliver Sponsors:

Mercy St. Mary's Hauenstein
Center, Grand Rapids
Rehab Specialists

Bronze Sponsor:

Bronson Healthcare System

In-Kind Sponsors:

Portage High School
Cheer Team
Big Moe's
Burger King

Committee:

Karen Freshwater, PA
Tiffany Hansard
Jennifer Knobloch
(All from Bronson
Neurosciences)



A Night of A Thousand Stars: Nov. 14, 2015

We hope you will join us for this year's gala, *A Night of A Thousand Stars*.

Ted Lindsay, Hockey Hall of Famer and Detroit Red Wing, is our Special Guest. This year, we are honoring volunteers who have given their all for several years on the planning committee to make this event exciting, inviting, and creative:

Lorraine Applebaum,
Carol Cummins, Deborah
Hardison Hill, Glen and Carol
Kramarich, Adele Pleatman,
Connie and John Spiteri and
William Suminski

We are very pleased to announce our current sponsors and invite others to join in:

Presenting Sponsor:
AbbVie

Media Sponsor:
HOUR Magazine

Platinum Sponsor:
Lance Industries

Gold Sponsor:
Esther and Neal Zalenko



Please join us for

A Night Of A Thousand Stars

with special guest Hall of Famer and Detroit Red Wing, Ted Lindsay

Saturday, November 14, 2015

6:00 - 10:00 pm

at the beautiful

**Ukrainian
Cultural Center**

26601 Ryan Road
Warren, MI 48091
(South of I-696/Eleven Mile,
on west side of Ryan Road)

Tickets: \$45 per person

Includes:

Dinner, Dancing, Valet Parking

Exciting Events

Silent Auction, 50/50 and Cash Raffles
(Express Checkout Available)

Live Entertainment Featuring:



Evening Attire

Help support MPF's
programs & services.
The tax-deductible portion
per ticket is \$5



Presenting Sponsor

abbvie

Platinum Sponsor



Media Sponsor



RSVP by Tuesday, Nov. 3, 2015 • Purchase tickets and/or make a donation for the event online at www.parkinsonsmi.org or by calling MPF Office 248-433-1011

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 60 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