

Quarterly Newsletter – March, April, May 2017
“FINDING YOUR WAY WITH PARKINSON’S DISEASE”
SUPPORT AND EDUCATION GROUPS

NOTE: Beginning this month the Newsletter will be mailed QUARTERLY
Please email your name to ellenmccauley@ongov.net to receive it by email

Regular Monthly Group Meetings

The Hearth at Greenpoint:

Monday, 3/6/17, 12:30-2 pm

Monday, 4/3/17, 12:30-2 pm

Monday, 5/1/17, 12:30-2 pm

150 Old Liverpool Road, Liverpool

Sharing & Support

“TeleMedicine and You” & Current

Research Studies at University of Rochester

Medical Center. Presenter: Mulin Xiong,

Health & Tech Research Associate

Annual Summer In-Door Picnic at The Hearth

Both groups are invited.

Brookdale Summerfield:

Tuesday, 3/14/17, 4-5:30 pm

Tuesday, 4/11/17, 4-5:30 pm

Tuesday, 5/9/17, 4-5:30 pm

100 Summerfield Village Lane

Sharing & Support

“Advanced Care Planning” – Nancy Aurelli,

Advanced Care Planning Advocate

Both groups are invited.

Summer In-Door Picnic at Brookdale Summerfield

Madison County Group Fourth Tuesday of Month 12:30-3 pm

Marshall Farms Foundation, 1978 New Boston Road, Chittenango. For Information Contact:

Martha at Marcar96@aol.com 315-655-3796 or 315-687-9014

Parkinson Symposium

Rochester, NY

April 8, 2017

contact@npfgreaterrochester.org

**CNY Huntington Disease
Support Group**

Information Contact: 315-656-8598

or jmirabito1@twcny.rr.com

Parkinson’s Dance:

Moving Through Possibilities

Regular Classes

Thursday’s at 1:45 pm.

117 Harvard Place, Syracuse (near
Westcott) For Information

Contact:

ParkinsonsDance@yahoo.com



ARE YOU INTERESTED IN PARTICIPATING IN A RESEARCH STUDY ABOUT PARKINSON'S DISEASE?

Researchers at Syracuse University are interested in investigating the use of Google Glass for three weeks on movement functions (e.g. balance, freezing, etc.) for people with Parkinson's disease. Google Glass is high-tech equipment you can wear during your daily activities. You can activate it by voice commands to play activity videos wherever you are.



Information about research:

- *This study requires 3 visits to Syracuse University to partake in interviews, questionnaires, and physical assessments (1-3 hour commitment each day) over a month period.*
- *The location is Women's Building, 820 Comstock Ave, Syracuse, NY*

Eligibility:

- Officially diagnosed with Parkinson's disease
- Native language: English
- Age: over 18

Please e-mail ttunur@syr.edu or call at **315-443-9332** if you are interested or would like more information.



Rochester NY Parkinson Disease Research Study Summary

Updated Tuesday January 17, 2017

Biotie (TOZ-PD):

- **Description:** Testing efficacy of Tozadenant for PD patients who experience end of dose wearing off while on carbidopa/levodopa
- **Inclusion Criteria:**
 - PD diagnosis of 3 years
 - Carb/levo at least 4 doses per day
 - Taking 1 other non-levodopa PD medication
- **Duration:** 18 months, 14 total visits (travel compensation available)
- **Contact:** Ashley Owen
 - (585) 341-7593
 - Ashley_Owens@URMC.Rochester.edu

Buspirone:

- **Description:** Testing tolerability of buspirone for treatment of anxiety in patients with PD
- **Inclusion Criteria:**
 - Can be on another anxiety medication
 - Not currently undergoing medication adjustment
- **Duration:** 12 weeks, 6 total visits
- **Contact:** Julia Iourinets
 - (585) 341-7433
 - Julia_Iourinets@URMC.Rochester.edu

Objective-PD:

- **Description:** Testing the feasibility of using a smartphone application to objectively and frequently assess the symptoms of Parkinson disease
- **Inclusion Criteria:**
 - With or without PD diagnosis (recruiting healthy controls)
 - iPhone (version 4s or higher) or Android smartphone
- **Duration:** 6 months, 3 visits total
- **Contact:** See page 2 for recruitment flyer

PDCNY:

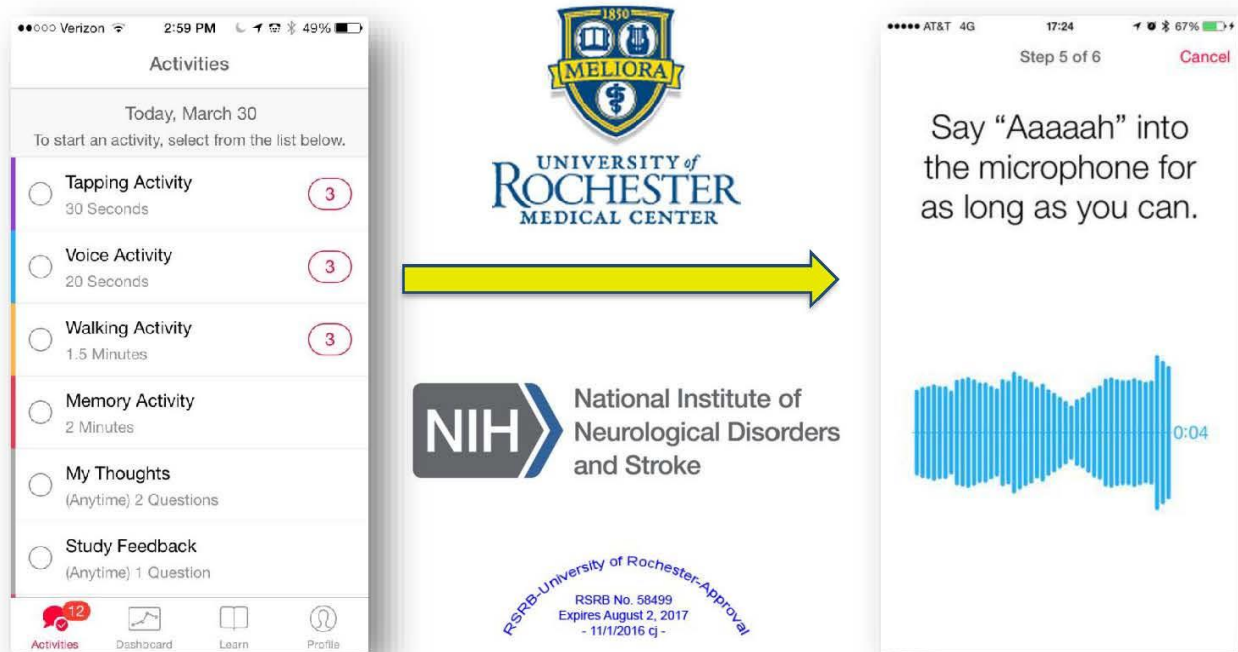
- **Description:** Care program aiming to provide underserved New Yorkers with Parkinson disease with free specialist care via virtual visits
- **Contact:** See page 3 for recruitment flyer

PPMI Genetic:

- **Description:** Biomarker study with free genetic screening, MRI, DAT, lumbar puncture - observational study
- **Inclusion Criteria:**
 - With or without PD diagnosis
 - Jewish ancestry or 1st degree relative with PD
- **Contact:** Ashley Owen
 - (585) 341-7593
 - Ashley_Owens@URMC.Rochester.edu

Objective-PD:

A Smartphone Research Study for Parkinson Disease (PD)



Help us develop a way to better track PD symptoms

Why participate? A novel smartphone application (app) has been developed to hopefully provide an objective, frequent measure of the effects of PD. We will compare the app's assessments with standard clinical evaluations to demonstrate the app's efficacy. This smartphone app could potentially improve neurologists' ability to treat patients with PD in the future. Subjects who successfully complete the study will receive a **\$200 gift card**.

Who can participate? People who have been clinically diagnosed with Parkinson disease AND generally healthy people (to serve as controls). Subjects must have an **iPhone (version 4s or higher)** or a **smartphone running Android**.

What would subjects be asked to do? 1.) Come to Westfall Clinic (Rochester, NY) for a baseline assessment and evaluations approximately 3 and 6 months later. These visits involve brief surveys, standard assessments performed by a neurologist, and a smartphone active tasks session. 2.) Complete the smartphone app's active tasks sessions – a set of brief activities involving, for example, walking (with phone in pocket), speeded on-screen tapping, voice production, memory – up to 3 times per day throughout the ~6-month duration of the study.

For more information or to enroll in “Objective-PD” study, contact:
Molly Elson (Study Coordinator) – (585) 276-6825 – molly.elson@chet.rochester.edu