

PSG NEWSLETTER



Parkinson Study Group, 1351 Mt. Hope Avenue, Suite 223, Rochester, NY 14620

PSG 21st ANNUAL MEETING

The PSG Annual Meeting was held on May 27th through May 29th at the Coronado Island Marriott Resort in San Diego, California. There were 217 attendees that included special guests, industry representatives and research sponsors. The meeting had a full agenda with the Second Clifford W. Shults Symposium, platform and poster research presentations, working group meetings, mentoring training module, study-specific meetings, eRT classes, and a new member's workshop.

This year the Cognitive/Psychiatric Working Group hosted the Second Clifford W. Shults Symposium entitled "Cognitive & Psychiatric Aspects of Parkinson's Disease". **Ellen Koutsky Shults** honored us with her presence, again, this year. **Ergun Uc** chaired the symposium which brought together many experts in the field of cognitive/psychiatry: **Alex Troster, Laura Marsh, Dan Weintraub, Irene Litvan, Jody Corey-Bloom, James Leverenz, Mickie Welsh, Karen Marder, Bernard Ravina, Mary Sano, Joe Friedman, and Mike McDermott**. This was well received and generated further discussion on potential clinical trials in the area of cognitive/behavioral dysfunction and dementia in PD.



Ellen Shults, Mickie Welsh, and Deborah Fontaine



Ergun Uc, Kelvin Chou, and John Growdon

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Attendees had many opportunities to learn about PSG research projects by viewing the 26 posters presented. The scope of the posters varied depending on the stage of the research, and ranged from describing the nature of project to final project results. In addition to the posters, presentations were given at the PSG Business Meeting. **Roger Kurlan** presented on The Parkinson's Disease Data and Organizing Center (PD-DOC) encouraging all PSG members to become familiar with this excellent resource (www.pd-doc.org). **Greg Pontone** gave a progress report on his Mentored Clinical Research Award project "Prevalence and familial aggregation of panic disorder in patients with PD". **Robert Hauser** presented his research on "ELLDOPA Database Analysis" and **Andrew Siderow** presented on his project "Impact of commonly-prescribed medications on PD progression". Karl Kieburz acknowledged the generous support of these projects and many others from the Parkinson's Disease Foundation, Michael J. Fox Foundation, NIH, NINDS, and the National Parkinson's Foundation.

The PSG Working Groups had very productive meetings. They are taking ideas generated from these meetings and developing proposals to submit to the Scientific Review Committee. **Dr. Richard Doty**, Professor and Director, Smell & Taste Center, University of Pennsylvania, was a special guest of the Other Non-Motor Features of PD working group. He will be assisting the group with the development of a proposal looking at olfaction in PD.



Richard Doty and Carlos Singer

PSG Annual Meeting, continued from front page...

Many members participated in the New Members Workshop facilitated by **Alice Rudolph**. They learned quite a bit about the history of the PSG and important issues such as conflict-of-interest policies. The slides of this presentation are posted on the PSG web site.

At the PSG Membership Business Meeting, a memorial for **Steven R. Schwid, MD** was given by Karl Kieburz. Dr. Schwid was a Professor of Neurology at the University of Rochester Medical Center who was well known for his compassionate care for his patients and his multiple sclerosis research. He participated in many PD trials and made many contributions to the PSG over the years. He will be missed by many and his work will resonate in the field for years to come.



***In memory...* Steven R. Schwid, MD**

Special honors were given to **David Oakes**. David was honored for his many years of service on the PSG Executive Committee. He will continue to work with investigators on their research projects. He now tips his hat to **Mike McDermott** to replace him on the PSG Executive Committee. **Cindy Comella** was also recognized for her exemplary service as Chair of the Mentoring Committee. The PSG welcomes **Joel Perlmutter** to replace her as Chair. **Jon Stoessl** joins him as Co-chair of the committee.



David Oakes, PhD

The PSG Election results were announced by Karen Rabinowitz. Members elected **Michael Schwarzschild** to the PSG Executive Committee. This concluded the term for **Bill Weiner** on the committee and his hard work and dedication to this committee was acknowledged. We thank nominees **Irene Litvan** and **David Simon** for accepting the nomination and acknowledge them for that honor. We also want to thank the PSG Nominating Committee consisting of **Bill Weiner, Chair, Karen Blindauer, Brad Racette,** and **Oksana Suchowersky** and all PSG members who voted.

A special training module hosted by the Mentoring Committee was held during the lunch hour on Thursday entitled "Training Mentors to be Mentors" presented by **Joel Perlmutter**. This focused on the growth of a physician-scientist with an emphasis on patient-oriented research. These slides are posted on the PSG web site and it is encouraged that those members who mentor others and particularly the members who have signed up to be advisors in the PSG Advisor Program use these as a reference.

To round out the meeting, an All Coordinators' Meeting and an All Investigators' Meeting was held. The coordinators discussed site budgeting, site selection and study initiation, and PSG background. The investigators discussed the site selection process, COI issues and PSG versus Study-based finances.

The meeting ended with a wonderful reception for all meeting attendees hosted by the Executive Committee in honor of coordinators.

Special thanks goes out to **Donna Moszkowicz** and **Jeanne Paiko** for arranging all meeting rooms, meals, AV needs, etc. Their close attention to detail and expertise in meeting planning made all the difference in the meeting success. We want to thank the project managers (**Emily Flagg, Rory Doolan, Alice Rudolph, Cheryl Halter, Cheryl Deeley**) for their work on the steering committee and study meetings. Also, a special thank you goes to the eRT mobile training lab team (**Cindy Casacelli, Connie Orme, Rory Doolan, Michele Goldstein and Alice Rudolph**) and CMI AV technicians for their hard work setting up equipment and trouble-shooting problems.

For more information regarding the Shults symposium, poster session, other meeting presentations and more meeting pictures, please visit the PSG web site at: <http://www.parkinson-study-group.org/What%27s%20New.html>

Next year's PSG Annual Meeting is on Wednesday, May 12-Saturday, May 15, 2010 at the Four Seasons Resort in Irving, Texas (<http://www.fourseasons.com/dallas/>).

PSG SYMPOSIUM

The 23rd Annual Symposium on Etiology, Pathogenesis, and Treatment of Parkinson's Disease and Other Movement Disorders will be held on **Sunday, October 11, 2009** at **The Baltimore Marriott Waterfront Hotel** in affiliation with the ANA meeting.

The PSG and HSG Symposia Committee members (**Roger Albin, Jang-Ho Cha (Chairs, respectively), Michael Schwarzschild, Tanya Simuni, Michele Tagliati, Guerry Peavy, Andrew Feigin, and Julie Stout**) will be rating and selecting regular and late-breaking research abstracts received for platform and poster presentations. When abstracts are selected, an abbreviated program will be posted on the PSG web site.

The two keynote speakers this year will be **Dr. Nicolaas Bohnen**, on "**Mobility impairment and cholinergic hypofunction in Parkinson's disease: in vivo imaging correlates**" and **Dr. Elan Louis**, on "**Essential Tremor: A Neurodegenerative Disease?**".



Dr. Bohnen is an Associate Professor of Radiology and Neurology, UM Functional Neuroimaging, Cognitive and Mobility Laboratory, University of Michigan Domino's Farms in Ann Arbor, Michigan.

Dr. Louis is a Professor of Neurology and Epidemiology and Associate Chairman of Neurology, College of Physicians and Surgeons and Mailman School of Public Health at Columbia University in New York.



The University of Rochester School of Medicine and Dentistry designates this educational activity for a maximum of 5.0 *AMA PRA Category 1 Credit(s)*TM. For more information, please visit the PSG web site at www.parkinson-study-group.org or the ANA web site at http://www.aneuroa.org/index.php?src=gendocs&ref=2009_Satellite_Affiliate_Meetings&category=ana_2009_Baltimore_default.

Study Updates

STEADY-PD

by Cheryl Deeley

STEADY-PD (**S**afety, **T**olerability, and **E**fficacy **A**ssessment of **D**ynacirc CR for PD) is nearing enrollment start-up. Two webinar orientation sessions have been conducted and sites are currently in the process of obtaining IRB approval. The date for the first subject enrolled is anticipated to be July 20, 2009. STEADY-PD is a pilot Phase II double-blind, placebo-controlled tolerability and dose finding study of isradipine CR in subjects with early Parkinson's disease. Isradipine CR is a dihydropyridine calcium channel blocker, approved for treatment of hypertension. This class of calcium channel blocking agents may provide neuroprotection and may reduce the risk of developing PD and slow disease progression. One hundred subjects with early PD will participate in this 12-month trial. Secondary endpoints include the impact of isradipine CR on motor disability, blood pressure, cognition, PD quality of life and PD-related disabilities. Dr. Tanya Simuni at Northwestern University and Dr. Kevin Biglan at the University of Rochester lead this study.

SURE-PD

by Alice Rudolph

SURE-PD (**S**afety of **U**rate **E**levation in **P**arkinson's **D**isease). Congratulations to Massachusetts General Hospital for being the first site to enroll subjects in SURE-PD! The other ten sites have completed their subcontract negotiations and are in various stages of their IRB submissions. The manuscript detailing the DATATOP urate results has been accepted for publication, and Michael Schwarzschild is anticipating that this will be a springboard for publicizing the SURE-PD study.

QE3

by Rory Doolan

The objective of the QE3 (Effects of Coenzyme Q₁₀ on Early Parkinson Disease) study is to evaluate the safety and effectiveness of high dosages of CoQ (2400 mg and 1200 mg vs placebo) in slowing clinical decline in patients with early PD. Participants, who are followed every four months over a 16 month period, must be diagnosed with PD within the last 5 years and not yet receiving dopaminergic therapy. Since recruitment began on January 12th 2009, the study has enrolled 240 of 600 planned subjects.

Study Updates (Con't)

PramiBID

by Alice Rudolph

On May 27th during the PSG Annual Meeting, PramiBID held its Closeout Meeting. At the meeting, the Investigators and Coordinators were informed of the study results and provided their feedback on a draft abstract. Currently the primary manuscript is starting to take shape, and plans are underway for making the results public in late September.

PostCEPT

by Emily Flagg

PostCEPT (A Longitudinal Observational Follow-up of the PRECEPT Study Cohort) is finishing up the second year of follow up visits. We are also in the process of completing the clinical data for the blood samples submitted to Coriell and it is anticipated that there will be close to 400 DNA samples catalogued and available to other researchers. A baseline manuscript was submitted to *Movement Disorders* by Bernard Ravina, MD and has been accepted.

PROBE

by Emily Flagg

PROBE (Blood α -Synuclein, Gene Expression, and Smell Testing as Diagnostic and Prognostic Biomarkers in Parkinson's Disease) completed enrollment at the end of 2008 with a total of 209 subjects (102 PD, 27 MSA, 26 PSP and 54 Healthy Control subjects). The database was locked in May 2009. The two research labs will be conducting biomarker analyses over the next several months and we anticipate having some initial results from these analyses towards the end of this year.

Information regarding PSG clinical trials can be found on the PSG web site or www.clinicaltrials.gov.

Also, the PSG Research Site Map is a great resource for referral contact information: <http://www.parkinson-study-group.org/PSGResearchSites.asp>. If you notice that your site contact information is not listed on the map, please notify us and we will make sure it is posted.

Credentials Committee

The Credentials Committee has credentialed 7 new investigators to the PSG since last report. We welcome the following investigators and coordinators:

Jacqueline T. Bernard, MD, University of Chicago, Chicago, Illinois
Joan Young, coordinator

Elmyra V. Encarnacion, MD, Scott & White Hospital/Texas A & M University, Temple, Texas
Patricia Simpson, coordinator

Heather Ene, MD, University of Colorado Denver, Aurora, Colorado
Pam Mettler, coordinator

Benzi M. Kluger, MD, MS, University of Colorado Denver, Aurora, Colorado
Teresa Derian, coordinator

New investigator and new PSG site!

Douglas Hobson, BSc, MD, University of Manitoba, Deer Lodge Hospital, Winnipeg, Manitoba
Shaun Hobson, coordinator

Elan D. Louis, MD, Columbia University, New York, New York

Janice Smolowitz, EDD, DNP, Columbia University, New York, New York
Ani Arkun and Angel Figueroa, coordinators

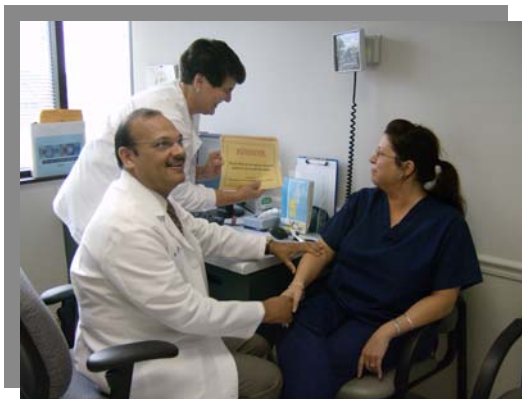
The Credentials Committee consists of **Karen Marder, Chair, Amy Colcher, Deborah Hall, Claire Henchcliffe, Christine Hunter, Stuart Isaacson, Mark Lew, Johan Samanta, Cathi Thomas, and Lin Zhang** with **Alice Rudolph, Karen Rabinowitz and Roseanna Battista, Ex-officio**.

You must be credentialed in order to participate in PSG studies. The Credentials Committee reviews applications about 4 times per year. The next meeting of the committee will be in September. Anyone interested in becoming a credentialed PSG investigator can contact Roseanna Battista for application materials (roseanna.battista@ctcc.rochester.edu).

Kudos to Sites!

The Gardner Center for Parkinson's Disease and Movement Disorders University of Cincinnati Neuroscience Institute by Maureen Gartner and Alok Sahay

While most significant medical research is conducted by scientists far removed from clinical practice, exceptional clinicians at The Gardner Center for PD and Movement Disorders within the University of Cincinnati's Neuroscience Institute combine superb clinical skills with medical research to make critical contributions to research into the most effective treatment of PD and related disorders. While in real estate, the phrase is "location, location, location" in research, "timing is everything." As with many Movement Disorders Centers, newly diagnosed patients can be hard to find, most referrals are either complicated cases or DBS surgery referrals.



Dr. Alok Sahay, Maureen Gartner at computer and Jennifer Dietz as a "volunteer patient".

At the University of Cincinnati Movement Disorders Center PI Dr. Sahay and coordinator Maureen Gartner found the time to find these patients. They enlisted the help of their colleagues with reminders about the PramiBID study at their monthly research meetings. In each clinic room posters were hung to advertise the current clinical trials and attract the patients' attention.



The coordinators are very creative in placing reminders on the physician's desk at each clinic to consider each patient as a potential research participant. All of these measures can be futile if the physician fails to mention participation in research trials as a way for a patient to be proactive with their disease process. Dr. Sahay believes "We consider each patient in clinic to have potential to be a research subject and thus contribute to understanding of the Parkinson's disease and other movement disorders."



Kudos for QE3 Study Subject Recruitment!

Rory Doolan, PSG project manager for **QE3**, would like to share kudos regarding the following sites on their recruitment of study subjects as of June 18, 2009. In general, QE3 is doing well with recruitment thanks to the efforts of all sites. *Congratulations!*

London Health (118) Jog/Cole: 9
Polyclinique Sainte-Anne (197) Pourcher/Bond: 12
U Penn (018) Siderowf/Altin: 8
IND (034) Russel/Cotto: 9
UC Davis (061) Zhang/Bautista: 10
Port City Neuro (193) Drasby/Lannon: 8
Rochester (001) Kurlan/Deeley: 9
Columbia (002) Waters/Arkun: 9

New Resource from PDtrials!

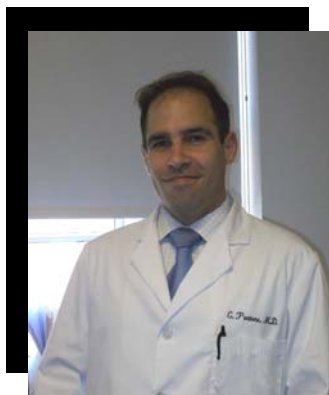
PDtrials has introduced a new resource that you may find to be a useful tool for people with Parkinson's who participate in studies at your research site.

Participating in Parkinson's Clinical Research: Questions to Ask, is a new publication that provides people with Parkinson's and others interested in clinical study participation with an extensive list of questions to ask to help ensure that they are educated and informed throughout the clinical research process. This publication was created by the Parkinson's Disease Foundation (PDF) in collaboration with a group of people with Parkinson's disease. If you would like to order print copies of this resource, please contact Nicole Rabin at (800) 457-6676 or nrabin@pdf.org.

If you would like to share kudos, please send to them to Roseanna Battista for future newsletters. Thank you!

Researchers in the News

The Mentored Clinical Research Award (MCRA) is an annual award program funded by a grant from the Parkinson's Disease Foundation to the PSG. The purpose of this grant is to support a new investigator for a 1 year project in patient oriented research in PD or other parkinsonian disorders under the mentorship of an experienced investigator with the goal of making this individual an independent researcher. **We highlight Dr. Pontone (08-09 awardee) and Dr. Peterson (09-10 awardee)...in their own words.**



**Gregory Pontone, MD,
Johns Hopkins University**

My interest in Parkinson's disease (PD) began in residency training while working in the Morris K. Udall Parkinson's Disease Research Center of Excellence at Johns Hopkins (PDRC). My first project while working in the PDRC investigated clinical factors associated with impulse control disorders in PD. As a psychiatrist, I was intrigued by the high prevalence and unique presentation of psychiatric disorders in PD. Inspired by my experience in the PDRC, I completed a two-year fellowship in geriatric psychiatry and movement disorders in order to develop the specialized clinical skills needed to begin a career focused on the investigation of psychiatric and other non-motor disturbances in PD. I joined the faculty at Johns Hopkins in 2008 as an assistant professor and now co-direct the Movement Disorder Psychiatry Clinic, which focuses on diagnosing and treating the neuropsychiatric aspects of PD and related disorders.

In 2008, I was awarded the PSG/Parkinson's Disease Foundation's Mentored Clinical Research Award for my project entitled "Prevalence and familial aggregation of panic disorder in patients with Parkinson's disease" and became a member of the PSG Mentoring Committee. Since then the focus of my research has been to investigate potential underlying causes and treatments for anxiety disorders in PD. Current and upcoming projects include: 1) an ongoing family study of panic and 'panic-like' disturbances in PD, 2) a pilot study to investigate panic disorder as a phenotypic subtype associated with genetic mutations in PD, 3) a pilot randomized-placebo controlled

clinical trial for the treatment of anxiety disorders in PD, and 4) the investigation of 'biomarkers' for anxiety disorders in PD using neuroimaging and other non-invasive techniques.



**Amie Peterson, MD,
Oregon Health and Science University**

I think I decided to pursue movement disorders on one of my first outpatient rotations as a junior resident. A person with Parkinson's disease (PD) had just had DBS implantation and was undergoing his first programming session; I was hooked. Over three years of fellowship first at UMass Medical Center and currently at Oregon Health and Sciences University (OHSU) I have continued to enjoy my clinical work with PD patients. Since at OHSU, I have also been involved in developing my own research.

I am grateful to the PSG and PDF for the funding towards "A Pilot Study of Balance and Vitamin D in Parkinson's Disease." The goal of the pilot study is to gain knowledge about vitamin D levels and balance performance in PD patients and use this information to optimally design an intervention trial of vitamin D. The idea to look at vitamin D came about shortly after starting fellowship at OHSU. OHSU's movement disorders group has 2 of the world's foremost experts on PD gait and balance; Dr. Fay Horak and Dr. Jay Nutt. In looking for novel therapies to improve balance in PD, we came across the endocrine literature that in studies of vitamin D supplementation not only did fracture rates decrease but often fall rates did as well. ***This is an ideal training level grant because it will help me gain data towards a possible intervention to improve one of the most disabling features of later stage PD, gait and balance problems.*** It will also allow me familiarity in working with state of the art equipment. Even if the results are negative I will be in a position to continue research of other novel therapeutics to improve balance. The funding from the PSG and PDF is instrumental in allowing the pilot project to progress in a rapid and fluid fashion towards an intervention trial.

This year's MCRA program will be announced in September with usual deadline for applications in March 2010. Please check the PSG web site for updates.

NEW INVESTIGATORS FORUM

The Mentoring Committee held a Mentorship Forum on **Monday, April 27th** at the **AAN meeting in Seattle**. The Forum was led by Joel Perlmutter with special guest William Weiner. The purpose of the program is to discuss methods, opportunities and obstacles in developing and funding clinical studies and to familiarize the participants with the PSG. Dr. Perlmutter emphasizes how to transition from fellow to junior faculty and how to grow a research career. Dr. Weiner shared the Chair's perspective in this process. The audience gained some valuable information and was encouraged to look into the PSG Advisor Program. *This meeting was supported by the Parkinson's Disease Foundation's Advancing Parkinson's Treatments Innovations Grant.*



Dr. Joel Perlmutter speaking to the participants

The Mentoring Committee is planning on having another forum at the AAN next year in Toronto. This year it will be a little different and more information will be announced this fall. *Stay tuned!*

PSG ADVISOR PROGRAM

The PSG Mentoring Committee has developed an Advisor Program for new investigators who are initiating a research career or continuing an existing research area. A bank of advisors is available to facilitate finding local mentors or funding sources for your research. If you would like to participate in this program, visit the PSG web site and complete an application form. The Mentoring Committee will review your application and respond back to you in a timely fashion.

A COMPREHENSIVE REVIEW OF MOVEMENT DISORDERS FOR THE CLINICAL PRACTITIONER

St. Regis Resort, Aspen, Colorado, July 27-30, 2009



Ann Stoutenburg, CCRC


Every year Stan Fahn, Joe Jankovic, and Mark Hallett direct a comprehensive CME course on Parkinson's disease and other movement disorders. Movement disorder fellows apply and about 20 are selected to receive a stipend to attend the course. The faculty also offer three fellowships for coordinators.




This year, Ann Stoutenburg was nominated and selected to participate. Ann works at the Clinical Trials Coordination Center at the University of Rochester as a Project Manager. *Congratulations Ann!*

For further information about the course you can contact any of the faculty or visit <http://ColumbiaCME.org>.

19th Annual Course
**A COMPREHENSIVE REVIEW OF
 MOVEMENT DISORDERS
 FOR THE CLINICAL PRACTITIONER**
St. Regis Hotel, Aspen, Colorado
July 27 - 30, 2009

for additional information: <http://www.ColumbiaCME.org> tel. 212-305-3334

Endorsed by:  The Movement Disorder Society

 <small>COLUMBIA UNIVERSITY</small> <small>College of Physicians and Surgeons</small> <small>STANLEY FAHN, M.D.</small> <small>Columbia University</small> <small>College of Physicians & Surgeons</small> <small>New York, New York</small>	 <small>BCM</small> <small>Baylor College of Medicine</small> <small>JOSEPH JANKOVIC, M.D.</small> <small>Baylor College of Medicine</small> <small>Houston, Texas</small>	 <small>WJN</small> <small>MARK HALLETT, M.D.</small> <small>Bethesda, Maryland</small>
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Calendar of Events

Sunday, October 11, 2009

23rd ANNUAL PSG SYMPOSIUM on PD and Other Movement Disorders, at ANA Annual Meeting, Baltimore, Maryland. More information is available on the PSG web site at: www.parkinson-study-group.org.

October 15-27, 2009

PDF 2nd Clinical Research Learning Institute (CRLI), multi-day training for people with Parkinson's disease. Hamilton Park Hotel & Conf Center in Florham Park, NJ. Contact Nicole Rabin for more information nrabin@pdf.org or see <http://pdf.org/en/crli>.

December 13-16, 2009

WFN XVIII World Congress on PD and Related Disorders, Miami, Florida USA. More information is on line at: www2.kenes.com/parkinson/Pages/Home.aspx or email parkinson@kenes.com.

May 12-15, 2010

PSG 22nd ANNUAL MEETING, Four Seasons, Irving, Texas. **Save the Date!** Contact Donna Moszkowicz for more information at: donna.moszkowicz@ctcc.rochester.edu.

September 28-October 1, 2010

WORLD PARKINSON CONGRESS, Glasgow, Scotland. Learn more at: www.worldpdcongress.org or contact Elizabeth "Eli" Pollard, Congress Manager, at info@worldcongress.org. PSG is proud to be an organizational partner of this event.



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Jeana Jaglin, RN, CCRC
Michael McDermott, PhD
Janis Miyasaki, MD
Joel Perlmutter, MD
Bernard Ravina, MD, MSCE
Michael Schwarzschild, MD, PhD
Caroline Tanner, MD, PhD
Frederick Wooten, MD

Ex-officio:

Roseanna Battista, BS
Donna Moszkowicz
Karen Rabinowitz, JD

Comments? Questions?

Please let us know...your comments and questions will be kept confidential. We also welcome your feedback on the newsletter and your ideas for topics for future newsletters.

Please send all correspondence to Roseanna Battista, roseanna.battista@ctcc.rochester.edu or contact Karl Kieburtz at karl.kieburtz@ctcc.rochester.edu or Karen Marder at ksm1@columbia.edu.

The Parkinson Study Group (PSG) is a non-profit, cooperative group of Parkinson's disease experts from medical centers in the United States and Canada who are dedicated to improving treatment for persons affected by Parkinson's disease.