PSG WORKING GROUPS

The date was **August 18, 2006** when our first 4 working groups were officially formed. **Drs. Growdon, Kang, Siderowf, and Singer** eagerly took lead of the Cognitive and Psychiatric, Biomarkers, Genetics and Environmental Risk, and Other Non-Motor working groups, respectively. Shortly after, in 2007, **Drs. Hauser and Okun** formed the Classic Motor and Functional Neurosurgical working groups, respectively. Along with a team of Co-Chairs including Ergun Uc, Kelvin Chou, Roger Kurlan, Claire Henchcliffe, Michael Schwarzschild, Lin Zhang, Mickie Welsh, Ivan Bodis-Wollner, Hubert Fernandez, Rajeev Kumar, and Tony Lang these working groups have worked hard over the years to generate proposals for new research studies.

Recently, terms of service expired for our leaders of the first 4 working groups and we want to especially acknowledge those who have rotated off or changed their positions within the PSG. These leaders have remained as active members in their working group. We thank them for their outstanding leadership, generosity of their time and guidance to generate ideas for research studies.

**Genetics and Environmental Risk Factors Group:**

André Siderowf  
Michael Schwarzschild

**Biomarkers Group:**

Un Jung Kang  
Roger Kurlan

Over the years, every working group has increased in size as PSG members were able to attend in-person working group meetings at every annual meeting. They have been called upon to assist in many proposals before submission to the PSG Scientific Review Committee (SRC). After the May 2010 annual meeting, each working group was charged to generate a 2-page concept proposal and submit them to the PSG Executive Committee. Working group leaders are currently reconvening to discuss the direction of their groups. **The new leadership teams are: Ergun Uc, Chair, Kelvin Chou and Laura Marsh, Co-Chairs for Cognitive/Psychiatric; Claire Henchcliffe, Chair, Peter LeWitt and Charles Adler, Co-Chairs for Biomarkers; Connie Marras, Chair, Lin Zhang and David K. Simon, Co-Chairs for Genetics/Environmental Risk; and Ivan Bodis-Wollner, Chair, Richard Doty and Ronald Postuma, Co-Chairs for Other Non-Motor.**

*Continued on Page 3...*
On May 24, 2007, when I was cleaning the trash can of my email box, surprisingly, I saw an email from Ms. Roseanna Battista. I was awarded the PSG Mentored Clinical Research Award (MCRA)!

My research on PD began in October 2005, when I graduated from Tufts School of Nutrition. I was fortunate to join Dr. Alberto Ascherio’s group as a post-doctoral fellow to study risk factors of PD. Because of my previous experience on methodology of dietary pattern (i.e., the combination of foods and nutrients), Alberto suggested me to start from this. By using data from two large prospective cohorts, I found that better diet quality was associated with lower risk of developing PD. Meanwhile, there were also some data from an earlier study showing that higher levels of endogenous antioxidant urate were associated with lower risk of PD. To further test the causality of this observed association, we developed an innovative dietary urate index and found a stronger association between the index and PD risk in a larger population of men.

In 2007, based on these exciting preliminary results, I was suggested by Alberto to submit a PSG/PDF MCRA grant to investigate whether these dietary pattern scores could also predict better survival among PD patients.

During my career development, two Ps — meeting great People at the right Place — were critical to lead me where I am today. After my MCRA was funded, I regularly met with Alberto to discuss this project. He gave me invaluable advice on study design, interpretation of data, manuscript writing, budget, and most importantly, how to become an independent investigator. Harvard is a wonderful place for junior investigators to start their career as you can meet all kinds of experts from different areas. For example, when I have any clinical questions of PD, I can always find good answers from Dr. Michael Schwarzschild, a neurologist at MGH. In the Harvard School of Public Health, I also took several advanced courses of neurological epidemiology and prospective data analyses to provide me necessary knowledge for conducting neuro-epidemiological studies independently.

I always consider the MCRA a milestone of my career path of studying neurological diseases. I would like to share some numbers. Before receiving MCRA, I had only two relevant abstracts. In contrast, after July 2007, I have published 23 manuscripts on neurological diseases (1st author on 15 of them) in Ann Neurol, Neurology, and other leading neurological journals. In these studies, we identified various predicting factors for the risk of developing PD, such as diet, pigmentation (hair color and MC1R gene), family history of melanoma, ibuprofen use, and several pre-motor factors (e.g., erectile dysfunction). Further, the number of journals inviting me to review manuscripts about neurological diseases has also jumped from 0 to 15. I have also been invited to present my studies at several national/international neurological conferences.

“I always consider the MCRA a milestone of my career path of studying neurological diseases.”
– X. Gao

Because of the MCRA, I was invited to participate on the PSG Mentoring Committee. Part of the committee’s activities was to review and select potential receivers for MCRA grants. As a junior investigator, I felt honored and privileged to get to review so many impressive grants. This also gave me an opportunity to see a grant from a totally different angle, which helped me to improve my grant writing skills.

Dr. Ascherio is a professor of epidemiology and nutrition at the Harvard School of Public Health and professor of medicine at the Harvard Medical School in Boston, Massachusetts. He also serves on the PSG Mentoring Committee.

Alberto Ascherio, MD, PhD

After I completed my MCRA project, I submitted my first NIH grant application. In 2009, this R01 project was funded by the NINDS, in which we are going to prospectively investigate risk factors and clinical consequences of restless legs syndrome, another dopamine-related common movement disorder, among ~100,000 men and women in US. I recruited my first post-doctoral fellow this year to help me to conduct this project.

After the PSG Mentoring Committee, I have served on another national committee: the Committee on Nutrition, Trauma, and the Brain, Institute of Medicine, National Academies in 2010-2011.

Xiang Gao is an Instructor in Medicine at Harvard Medical School. He is an Associate Epidemiologist at Brigham and Women’s Hospital and a Research Scientist at the Harvard School of Public Health. The MCRA is funded by a grant from the Parkinson’s Disease Foundation.
WORKING GROUPS
(Continued from front page…)

This year a page dedicated to the working groups was created on the PSG website, click here to learn more and to join a working group... PSG Working Groups.

In addition to generating proposals, several working groups have hosted the annual Shults Symposium. In 2008, the Biomarkers Working Group presented on potential biomarkers for future clinical trials and scientific debates on these markers. In 2009, the Cognitive/Psychiatric Working Group presented on cognitive and psychiatric aspects of PD. This year, the Genetics/Environmental Risk Working Group presented on current issues in genetic and environmental contributions to Parkinson’s disease and other movement disorders. It was the first year that this symposium was combined with the PSG Annual Symposium usually held in the fall. This was well received and attendance was much better than in previous years when held in conjunction with the ANA meeting.

The Classic Motor Working Group is busy planning next year’s symposium with the PSG Symposia Committee and the theme is “Movement Disorders: Beyond the classic model of the basal ganglia”. This will be held on Friday, May 13, 2011, from 1:00-6:00 p.m. in Irving, Texas during the PSG Annual Meeting. The deadline for submission of regular abstracts is January 21, 2011. Please visit the PSG website for more information and to obtain a Call for Abstracts form.

We would encourage anyone with a research idea to make use of the working groups and the PSG Advisor Program. They are available to assist you and develop your ideas further. The PSG “toolkit” on the web site is another valuable tool to check out available PSG databases for datamining projects and to see what has been done or what is in progress. Peggy Auinger, the PSG statistician involved in many datamining projects, is available to contact to discuss feasibility of your idea, if needed.

Meetings of each working group will be held at the PSG Annual Meeting throughout the day on Friday, May 13, 2011 with no overlap and we hope you can take advantage of attending as many as possible!

PSG New Investigators Forum
A program will be planned for April 2011 during the AAN Annual Meeting in Honolulu, Hawaii. Further details will be out soon!

PSG Meeting/PSG Symposium
The PSG 23rd Annual Meeting and 25th Annual PSG Symposium are scheduled for May 12-14, 2011. It will be held at the same venue as this year – the Four Seasons, in Irving, Texas. Invitations and registration will be sent in March 2011. If you are interested in submitting an abstract for the symposium, please visit the PSG website for a form and more details. The deadline for receipt of abstracts is Friday, January 21, 2011 and late-breaking research abstracts are due Friday, February 25, 2011. New this year is the PSG Introduction to Clinical Trials course hosted by the PSG Mentoring Committee MCRA awardees to be held Friday, May 13, 12:00-1:00 p.m. Many other activities are planned and we look forward to an interesting program this year.

PSG MCRA PROGRAM
This award is funded by a grant from the Parkinson’s Disease Foundation (PDF) to the Parkinson Study Group (PSG). The PDF partnered with the PSG to encourage the professional and scientific development of young investigators on their path to independence. This grant supports a new investigator for a one year project in patient oriented research in Parkinson’s disease or other parkinsonian disorders under the mentorship of an experienced investigator. The training should lead a junior investigator to gain skills in clinical research. The research plan should address unmet needs of people living with PD, have the potential for broad application among the PD community, and lead to advances in clinically relevant treatment options. Please see the RFP on the PSG website at www.parkinson-study-group.org. The submission deadline is Friday, March 25, 2011.

PSG Advisor Program
Last year, the recipient of the MCRA benefitted from connecting with an advisor while preparing his grant. We want to encourage new investigators who are initiating a research career or continuing an existing research area to apply. This valuable resource is managed by the PSG Mentoring Committee and a bank of advisors are ready to help you find a local mentor in your area (both research and geographic) or help you find specific research funding sources (foundations, etc.) for your research. If you would like to participate in this program, please complete the application form on the PSG website.
STUDY UPDATES

SURE-PD by Alice Rudolph
SURE-PD (A randomized, double-blind, placebo-controlled, dose-ranging trial of oral inosine to assess safety and ability to elevate urate in early Parkinson's disease) held an Investigators/Coordinators Meeting in NYC on 10/18/10 to discuss impediments to enrollment and brainstorm solutions. Subsequently a suite of recruitment materials has been prepared for site use. In addition, the 17 sites are sending study materials to 4200 local neurologists identified through a national professional organization. Thanks to resources provided at the PI's/Co-PI's institutions, the envelopes have been hand addressed, and site Investigators are personally signing the enclosed letters. The video "Seeking better treatments for Parkinson's disease: The SURE-PD Trial" has been posted to YouTube at SURE-PD Trial, and a link is available on the Parkinson Study Group website. The SURE-PD trial is funded by the Michael J. Fox Foundation.

QE3 by Karen Helles
QE3 (Effects of Coenzyme Q10 on Early Parkinson Disease) has completed enrollment of 600 subjects as of October 29, 2010 at 67 sites. The active participants will be followed every 4 months over a 16 month period with completion of all subject visits expected by February 2012. We would like to thank and congratulate all of the sites who are participating in QE3 for their dedication and hard work in helping us reach this milestone.

The objective of the QE3 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. This study is funded by the National Institute of Neurological Disorders and Stroke (NINDS) of the National Institutes of Health (NIH). Further details of the study may be found on the PSG web site.

PostCEPT by Emily Flagg
PostCEPT (A Longitudinal Observational Follow-up of the PRECEPT Study Cohort) continues with subjects completing the fourth year of follow up assessments. Subject retention has remained high, with about 87% of the cohort actively being followed.

PROBE by Emily Flagg
PROBE (Blood α-Synuclein, Gene Expression, and Smell Testing as Diagnostic and Prognostic Biomarkers in Parkinson’s Disease) is continuing with the analysis phase of the synuclein and transcriptomics data. A manuscript will be prepared to report on the results and is planned for submission during the first quarter 2011.

STEDY-PD by Cheryl Deeley
STEDY-PD (Safety, Tolerability, and Efficacy Assessment of Dynacirc CR for PD) completed study enrollment on October 31, 2010. This was accomplished with the recruitment of 5 rescue sites which brought the total number of participating sites to 21. An interim analysis was completed in August after the first 50 subjects had enrolled and completed the titration phase of the study. Based on that blinded analysis, the highest study medication dosage was removed from the titration schedule for incoming subjects because it had a greater than 30% intolerability compared to placebo. STEADY-PD is a pilot Phase II doubleblind, 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. 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. This study is funded by the Michael J. Fox Foundation.

SPIN-PD by Jennifer Harman
SPIN-PD (SPectroscopy IN Diagnosis of PD) The purpose of the study is to assess the potential for biomarkers in the diagnosis of PD. Thirty-seven research centers across North America enrolled 195 PD subjects and 119 Healthy Controls. Enrollment has ended and analysis is underway. We anticipate the analysis will be finished in late winter or early spring. This study was conducted with funds provided by Molecular Biometrics, Inc. made possible through grants from the Michael J. Fox Foundation. Dr. Hyman Schipper, Medical Director-Neuroscience, is the Company’s principal investigator for this study.

PROGENI by Cheryl Halter
PROGENI (Parkinson’s Research: The Organized Genetics Initiative). The PROGENI study recruitment is closed. For additional information, please call 1-888-830-6299 or outside of the United States, call 1-317-274-5734.

PramiBID – 2010 publication
Kudos to Sites!

**STEADY-PD KUDOS! by Cheryl Deeley and Nita Gardiner**

Kudos go to the entire STEADY PD team for completing enrollment on time! Thanks to everyone for their contribution. Special thanks go to our “Rescue sites” who brought on many of the last subjects to help us reach our goal of 100! Our rescue sites include: Institute for Neurodegenerative Disorders, Michigan State University, Park Nicollet, Cleveland Clinics and University of South Florida. Great team work everyone!

**QE3 KUDOS! by Karen Helles**

Kudos to all of the QE3 sites for completing study enrollment on October 29th. The top four enrolling sites are Site 197 with 21 subjects enrolled (Dr. Emmanuelle Pourcher, Investigator; Louisette Bond, Coordinator); Site 220 with 20 subjects enrolled (Dr. Pinky Agarwal, Investigator; Bari Dorward, Coordinator); and Sites 005 and 118 with 19 subjects enrolled (Dr. Katie Kompoliti, Investigator; Lucia Blasucci, Coordinator) and (Dr. Jog Mandar, Investigator; Linda Cole, Coordinator).

We would also like to recognize the extraordinary efforts of Sites 047, 135 and 169 in increasing exposure of the QE3 study to minority populations. These activities included mailing informational physician letters; meeting and speaking with local health care providers whose clinical practice includes high numbers of minority patients; holding lunches and dinners for patients, physicians and members of the community who are involved with PD patients; developing and distributing Spanish translated patient brochures, to name a few.

Site 047 – Univ of Tennessee HSC - Investigator: Ronald Pfeiffer, Coordinator: Brenda Pfeiffer (not pictured)

Site 135 – SUNY Downstate – Investigator: Ivan Bodis-Wollner, Coordinator: Sofya Glazman

Site 169 – Hershey Medical Center - Investigator: Thyagarajan Subramanian, Coordinator: Donna Stuppy Ford

The Parkinson Disease and Related Disorders Clinic which includes the PD Research Center of the State University of New York (SUNY) and Kings County Hospital Center (KCHC) Clinic gained “Center of Excellence” designation in April 1995. SUNY and KCHC are on opposite sides of Clarkson Avenue, in the Flatbush section in Brooklyn. The majority of the population we serve is minority groups: mostly black, Afro-Americans and Haitian immigrants. This poses challenges and opportunities. We have gained the confidence of persons cared for in our clinic not only as patients but also as candidates for research studies. We believe that our grassroots, individual approach is responsible for the mutual respect patients have for persons who work at the Clinic and for the respect our Clinic staff has for our patients. We spend time getting to know our patients, their families, their interests, problems, one by one. We believe the time we spend with each patient, has helped. We are happy to be able to participate in their medical care and in research which ultimately will help the specialized neurological care of our population.

Do you have kudos to share or tips on conducting clinical trials that would be helpful to others?

_We’d love to hear from you!_

_Just send a note to Roseanna Battista at roseanna.battista@ctcc.rochester.edu_

_Thank you!_
The PSG was selected by the Legends 102.7 radio station to receive a portion of the proceeds for Parkinson’s research from a dance held on October 23, 2010 in Rochester. Radio personality, KB Cooper, organized the “Last Call for Fall” event with others at the station. It was a great night of dancing and fun with raffles and a photo booth. Legends contributed $1,000 to the PSG with a generous additional contribution from the station’s owner, Mr. Don Crawford, Jr. KB’s father had Parkinson disease and she joins many others who share their own personal stories about this very debilitating disease.

This contribution will be used toward our research projects and we hope that one day there will be a cure.

Anyone wishing to contribute to the PSG can do so by sending a check made out to the Parkinson Study Group and mailing it to 1351 Mt. Hope Avenue, Rochester, NY 14620 or visit our website at www.parkinson-study-group.org to donate on line. Other ways to contribute would be to consider participating in a current PSG Study or consider autopsy or brain donation to help further PD research. If you want to learn more about study participation in general, visit www.clinicaltrials.gov.

For more information regarding PSG clinical trials, please visit the PSG website.
Calendar of Events

January 21, 2011
PSG Symposium Call for Abstracts – deadline for receipt of abstracts. Late Breaking Research Abstracts due: February 25, 2011

March 25, 2011
Deadline for submission of applications for PSG/PDF Mentored Clinical Research Award (MCRA)

April 2011
PSG PRESENTS: STARTING A CLINICAL RESEARCH CAREER – CLUES FOR SUCCESS, hosted by the PSG Mentoring Committee. To be held at the AAN Annual Meeting in Hawaii. Date and time to be determined.

May 12-14, 2011
PSG 23rd ANNUAL MEETING and PSG 25TH ANNUAL SYMPOSIUM, Four Seasons, Irving, Texas.

Reminder:

The PSG posts Academic Positions on the PSG web site and this is very helpful to fellows or other researchers when looking for employment in the field. If you have any open academic or staff position(s) available within your institution, please send an email advertisement to Donna Moszkowicz, donna.moszkowicz@ctcc.rochester.edu, for posting.

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, mailto:roseanna.battista@ctcc.rochester.edu or contact Karl Kieburtz at karl.kieburtz@ctcc.rochester.edu or Karen Marder at mailto:ksm1@columbia.edu.