Together We Can Make A Difference

ADVANCE RESEARCH: GET INVOLVED

Research Opportunities with the Emory Parkinson's Disease and Movement Disorders Program

EMORY UNIVERSITY

Jean and Paul Amos Parkinson's Disease and Movement Disorders Program

Working Together

Emory University is a leading clinical and basic research center for Parkinson's Disease and other movement disorders including dystonia, essential tremor, Huntington's Disease, and Tourette's syndrome. As a part of the Emory School of Medicine, our Center serves as a major referral center for both adult and pediatric patients in Atlanta, the state of Georgia, and the Southeastern United States.

Our patient's lives are improved from the synergy found in a setting like Emory. We bring together medical discoveries through research and provide the newest, most beneficial treatments available that range from diagnosis to rehabilitation. Our neurosurgeons, neurologists, psychologists and researchers work together to tailor treatment for the specific needs of each patient.

The twelve clinical faculty members in Emory Movement Disorder program see approximately 6,000 patients annually of which 3,000 have Parkinson's disease or parkinsonism, making this probably the single largest specialty group for this condition in the world.

The program is internationally recognized for the pioneering work of Drs. Mahlon DeLong, Thomas Wichmann and others in the group who played integral part in the discovery of brain circuitry changes relating to Parkinson's disease which lead to novel surgical therapies that were brought into clinical practice worldwide. The Emory program is also internationally recognized for its advanced work on the role of pesticides and other environmental influences in Parkinson's disease, as well as being the central site for the Dystonia Coalition.

It would be impossible to list here all the ways we have enhanced our delivery of care to patients and family members. This work is possible with the help of individuals such as yourself. We've made outstanding progress, but we haven't uncovered every opportunity. Each discovery brings us closer to unlocking the answers to neurological brain disorders. It's gratifying to have your support and vote of confidence in our ability to make a difference. Our only hope for change is to work collectively on the issues we know no one can tackle alone.

Sincerely

Stewart Factor, DO
Vance Lanier Chair in Neurology
Director, Emory Parkinson's Disease and
Movement Disorders Program

Research Opportunities

What is a clinical research study?

A clinical research study is a carefully designed scientific evaluation of an investigational drug conducted by doctors. Clinical research studies help to answer important medical questions, such as how a new drug acts in the body, how it affects certain diseases or conditions, and whether or not it is safe for wider use. Because clinical studies are voluntary, participants are free to leave the study at any time for any reason.

Why are clinical research studies important?

Clinical studies are the only way new medications for diseases can become approved for widespread public use. They provide a way to test drugs so we will know if they are safe and effective. People who participate in clinical studies contribute to research that will further the knowledge about the treatment of diseases.

PARKINSON'S DISEASE

IPX203

Due to the frequency and impact of "OFF" states in people with Parkinson's disease, patients need a medication that can extend the "ON" state. This clinical trial is looking at an experimental study medication that can provide the same benefit in 2-3 doses per day. The requirement consists of 8 visits in approximately 24 weeks. Carbidopa/Levodopa and experimental medication will be provided to the participant.

ELIGIBILITY

40 years of age or older
Have a medical diagnosis of Parkinson's disease
Experiencing 2.5 hours of "Off" time per day
Taking at least 4 doses of carbidopa/levodopa per day

CONTACT

Barb Sommerfeld
bsommer@emory.edu
404-712-6997

SEP361-203

If you have Parkinson's disease, your brain will change over time. This may cause some people to experience symptoms such as visual hallucinations (seeing things that aren't there), delusions (such as paranoia), or illusions (thinking something is real when it is not). Sometimes this is referred to as Parkinson's disease psychosis, which is common in people with Parkinson's disease. This study will evaluate how well it works treating psychosis symptoms.

ELIGIBILITY

Male and female subjects aged 55 years of age or older
Diagnosed with PD for at least one-year
Ability to have a caregiver to attend all study visits
of at least 1 year

CONTACT

Elaine Sperin
esperin@emory.edu.edu
404-712-7044
404-712-7044

Research Opportunities

PRESENCE

Cognitive impairment in subjects with Parkinson's disease (PD) is common. As the disease progresses many subjects develop dementia. This clinical trial is looking at a new medication to treat Dementia without making PD symptoms worse.

ELIGIBILITY

Male and female subjects aged 40 to 85 years
At least 2 years of PD symptoms
Be on stable doses of medications
Women of childbearing potential are excluded

CONTACT

Cathy Wood-Siverio
cwoodsi@emory.edu
404-712-6988

BOSS PD

12-week trial comparing behavioral therapy to drug treatment for those experiencing urinary issues with Parkinson's disease. All study visits are individually scheduled at the Atlanta VA Medical Center.

ELIGIBILITY

Diagnosed with Parkinson disease
Experiencing urinary issues
Able to attend clinic appointments

CONTACT

Taressa Sergent
taressa.sergent@va.gov
404-321-6111 ext 205303

AADC Gene Therapy in PD

Gene therapy is being investigated as a way to treat disease at its source by delivering new instructions, or genes, into cells affected by PD. In our study, this is done using viruses, or vectors that are naturally capable of transferring genes into cells and not known to cause illness. In theory, a vector could be likened to an envelope carrying a message, or gene, to specific brain cells. Once the gene has been transferred inside the cell, it is then read by the cell. The brain cells would then use their normal machinery to produce the gene product, with the goal of restoring typical cell function. In this case, the goal is to replace the AADC gene with the intention of converting more levodopa to dopamine. The gene therapy product in this study, adeno-associated virus, is a type of vector capable of delivering genes to brain cells. It has been safely used in other clinical trials for investigational gene therapy products. The vectors retain no genetic elements of the virus and are incapable of initiating a viral infection.

ELIGIBILITY

Ages 40-75
Diagnosed with PD for at least 5 years
Have several hours of "OFF" time each day
Willing to be monitored closely and complete 19 visits over 3 years

CONTACT

Carole Seeley
carole.seeley@emory.edu
404-727-8748

Eye Tracking

Parkinson's disease patients interested in participating in a study looking at eye movement abnormalities. We are investigating the relationship between REM sleep disorder and PD. It is a one -time visit for PD and healthy control participants. The 3-hour visit will consist of several motor movement tasks and assessments, a brief cognitive assessment and several eye tracking assessments. Patients with REM sleep disorders will be invited back for yearly assessments but are under no obligation to return

ELIGIBILITY

Diagnosis of PD
Ability to undergo 3-hour visit
Willingness to wear headgear with attached cameras that focus on the pupils while performing tasks on the computer

CONTACT

Jonna Seppa
jseppa@emory.edu
404-727-1509

Research Opportunities

Neuromodulation Longitudinal Study

This study reviews patients' medical records to investigate long-term patterns and trends in patients that have undergone deep–brain stimulation surgery or other neuromodulation surgeries. We here at Emory have had the privilege of seeing and treating many neurosurgery patients and a wealth of information is at our finger-tips. The information related to your care at Emory could assist in further developing and improving our methods and procedures. We just need your permission to add your medical records to our research database.

CONTACT

Jonna Seppa • jseppa@emory.edu • 404-727-1509

EEG Study

We investigate the brain wave activity of movement disorder patients in this study. Most visits will last about 3 hours and will consist of one or two EEG recordings, a short cognitive assessment and a short depression survey. With careful assessment of the brain activity, we hope to learn more information so that patient treatment outcomes could be optimized in the future.

ELIGIBILITY

Diagnosis of PD, atypical PD
Healthy controls willing to participate
PD or atypical PD participants willing to come in "off" their PD medications have the EEG recording then take their normal dose of PD medications and repeat the EEG while in the "on" state

CONTACT

Jonna Seppa
jseppa@emory.edu
404-727-1509

Intraoperative Physiology

If you are planning to have deep-brain stimulation (DBS) or lesioning surgery to treat your movement disorder please consider participating in this trial which investigates specific parts of the brain that are involved in movement. In this study we request the patient to permit us to record the data from your regular surgery and the patient is welcome to participate in optional additional recordings during your surgery involving simple motor tasks and an optional research MRI before the surgery.

CONTACT

Jonna Seppa • jseppa@emory.edu • 404-727-1509

Automated Programming

Patients that have already had DBS surgery are invited to participate in this one-time 3 hour visit to the Brain Health Center where a new method of programming your DBS device will be tested. The clinical standard for adjusting your DBS device is currently done by a clinician administering motor tasks and fine-tuning your DBS device settings based on your performance on those tasks. In this study we investigate the use of a computer designed to do the same. The patient should be prepared to have their device "OFF" and also adjusted to different settings. The patient's DBS device will be returned to its clinically-determined optimal setting before the patient leaves.

CONTACT

Jonna Seppa • jseppa@emory.edu • 404-727-1509

Research Opportunities

NeuroDerm

A new clinical trial using a levodopa solution which is delivered continuously to the patient is being conducted to see if "off" time can be reduced.

ELIGIBILITY

Aged 30 years and older
Experiencing "off" time despite taking PD medications as directed
Taking PD medications at least 3 times a day

CONTACT

Jonna Seppa
jseppa@emory.edu
404-727-1509

Rad-PD

This is a national database registry study for those Parkinson's patients who undergo Deep Brain Stimulation. The researchers would like to follow these patients for 5 years after their surgery. Participate in this study simply by signing up before your surgery and by completing questionnaires during your regular clinic visits.

ELIGIBILITY

Ages 18 and older
Planning to undergo deep brain stimulation surgery for treatment of Parkinson's Disease at Emory
Willing to fill out questionnaires approximately once a year after your surgery at regular clinic visits

CONTACT

Jonna Seppa
jseppa@emory.edu
404-727-1509

GLIDE PD

Subjects are enrolled in this 14-week clinical trial for a new medication to decrease dyskinesia, a common side-effect of levodopa treatment. This study will see participants for 9 scheduled visits.

ELIGIBILITY

Diagnosis of PD
Ages 30-85
Experiences dyskinesia
Willing to come into the clinic at 8AM for 5-6 hours per visit for 9 visits

CONTACT

Jonna Seppa
jseppa@emory.edu
404-727-1509

MRI of Locus Coeruleus Norephinephrine System in PD

We are recruiting healthy volunteers and patients with Parkinson's disease, MSA, PSP or RBD to participate in an MRI study of Parkinson's disease. The aim is to develop new imaging tools to help study Parkinson's disease and develop new treatments. This is a one visit study, which may be repeated in 16 months. The visit will take approximately 4 hours and will include clinical exams, questionnaires, vital signs, blood draw, followed by a 1-hour MRI done at Emory Hospital.

ELIGIBILITY

Have mild to moderate Parkinson's disease, MSA, PSP or RBD
Adults over the age of 30
Do not have any contraindication for MRI (metal fragments in your body, pacemaker, etc.)
Are not pregnant or claustrophobic

CONTACT

Cathy Wood-Siverio
404-712-6988
cwoodsi@emory.edu

DYSTONIA AND TREMOR

DYSTONIA COALITION PROJECTS

Longitudinal observational study to see how dystonia changes over time.

ELIGIBILITY

Any isolated (formally primary) dystonia

CONTACT

Adam Cotton
akassem@emory.edu
404-727-3381

HUNTINGTON'S DISEASE

ENROLL

Is a longitudinal, observational, multinational study that will integrate two existing Huntington's Disease (HD) registries, REGISTRY in Europe and COHORT in North America and Australia, while also expanding to include sites in Latin America and Asia.

ELIGIBILITY

Age 18 and older
Carriers: This group comprises the primary study population and consists of individuals who carry the HD gene expansion mutation.
Controls: This group comprises the comparator study population and consists of individuals who do not carry the HD expansion mutation.

CONTACT

Elaine Sperin, LPN
esperin@emory.edu
404-712-7044

KINECT-HD

A double blind placebo-controlled study to evaluate Valbenazine given once daily for the treatment of Chorea in adult subjects with HD.

ELIGIBILITY

Male or Female 18 to 75
Diagnosed with chorea at or before screening
Have a confirmed genetic test result of >37

CONTACT

Elaine Sperin, LPN
esperin@emory.edu
404-712-7044

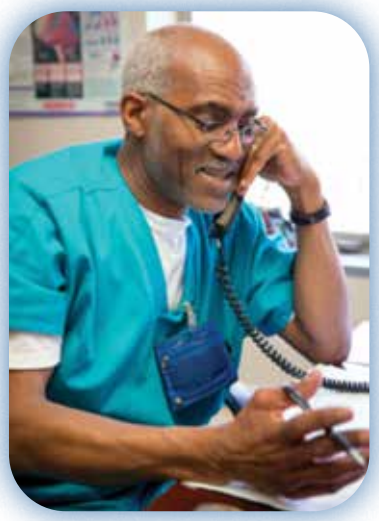
TOURETTE'S SYNDROME

None at this time.

Research Opportunities

ATAXIA

FA-COMS



This is an observational study of patients with Friedreich's ataxia. Patients will be assessed on an annual basis to evaluate their symptoms over time. Physical exams, fine motor movements, visual acuity, cardiac evaluations (if ordered by a cardiologist) and patient questionnaires will be collected annually. Additionally, blood will be collected for DNA (baseline only) and RNA testing as well as frataxin levels and a cheek swab for frataxin levels will also be collected annually.

ELIGIBILITY
Diagnosis of FA by clinical exam or genetic testing

CONTACT
Becky McMurray, RN
404-712-7013
rmcmurr@emory.edu

Natural History of and Genetic Modifiers in Spinocerebellar Ataxias

Spinocerebellar ataxias (SCA) are genetic neurological diseases that cause imbalance, poor coordination, and speech difficulties. There are different kinds of SCA and this study will focus on types 1, 2,3, and 6 (SCA 1, SCA 2, SCA 3 , also known as Machado-Joseph disease and SCA 6). The diseases are rare, slowly progressive, cause increasingly severe neurological difficulties and are variable across and within genotypes. The purpose of this research study is to bring together a group of experts in the field of SCA for the purpose of learning more about the disease. Patients who enter this study will be evaluated every 6-12 months. Physical exams, fine motor testing and questionnaires will be collected. At study entry only, blood will be collected for DNA testing to confirm the diagnosis.

ELIGIBILITY
Diagnosis of SCA type1, 2, 3, 6, 7, 8 or 10 by clinical exam or genetic testing

CONTACT
Carole Seeley
carole.seeley@emory.edu
404-727-8748

OTHER: MSA, PSP, TARDIVE DYSKINESIA

Eye Tracking

PSP or MSA patients interested in participating in a study looking at eye movement abnormalities. It is a one-time visit for PSP, MSA and healthy control participants. The 3-hour visit will consist of several motor movement tasks and assessments, a brief cognitive assessment and several eye tracking assessments.

ELIGIBILITY
Ability to undergo 3-hour visit
Willingness to wear headgear with attached cameras that focus on the pupils while performing tasks on the computer

CONTACT
Jonna Seppa
jseppa@emory.edu
404-727-1509

M-Star

This year-long clinical trial for patients with MSA tests a new medication to treat the symptoms of MSA.

ELIGIBILITY

Diagnosis of MSA
Age 40-75 years
Can take 10 steps without assistance from a person or device.
Able to tolerate 1-hour MRI
Must have reliable caregiver to accompany participant to all study visits

CONTACT

Jonna Seppa
jseppa@emory.edu
404-727-1509

MRI of Locus Coeruleus Norephinephrine System

We are recruiting healthy volunteers and patients with Parkinson's disease, MSA, PSP or RBD to participate in an MRI study of Parkinson's disease. The aim is to develop new imaging tools to help study Parkinson's disease and develop new treatments. This is a one visit study, which may be repeated in 16 months. The visit will take approximately 4 hours and will include clinical exams, questionnaires, vital signs, blood draw, followed by a 1-hour MRI done at Emory Hospital.

ELIGIBILITY

Have mild to moderate Parkinson's disease, MSA, PSP or RBD
Adults over the age of 30
Do not have any contraindication for MRI (metal fragments in your body, pacemaker, etc.)
Are not pregnant or claustrophobic

CONTACT

Cathy Wood-Siverio
404-712-6988
cwoodsi@emory.edu

REM Sleep behavior disorder (RBD)

NAPS

Purpose is to collect blood samples from individuals with RBD to use in future studies, in order to develop tests for identifying individuals at high risk of developing neurodegenerative diseases. Participants are given the optional consent to collect cerebrospinal fluid (CSF) from lumbar puncture to use in future studies. All blood and spinal fluid are de-identified and stored at a national repository for future research. Two research visits 1 year apart. Visits will take approx.4 hours to complete.

ELIGIBILITY

Diagnosed Rapid Eye Movement (REM) sleep behavior disorder (RBD) from previous sleep study.

CONTACT

Cathy Wood-Siverio
cwoodsi@emory.edu
404-712-6988

RBD

One visit study for those diagnosed with REM sleep behavior disorder. The visit includes 4 tubes of blood, assessments and questionnaires.

ELIGIBILITY

Diagnosed Rapid Eye Movement (REM) sleep behavior disorder (RBD) from previous sleep study.
18 years of age or older.

CONTACT

Cathy Wood-Siverio
cwoodsi@emory.edu
404-712-6988

Research Opportunities

COMING SOON:

Ataxia:
Ataxia surgical trial

FOR MORE INFORMATION:

- To make a clinical appointment call 404-778-3444
- APDA call Christabelle Auguste at 404-712-7091
- NPF contact Tammyjo Best at 404-712-6990
- For more information about community programs contact Cornelya Dorbin at 404-712-1416.

PARKINSON'S DISEASE COMPREHENSIVE CARE CLINIC AT EMORY UNIVERSITY

The Emory Movement Disorders Program created the Merrie Boone Comprehensive Care Clinic (CCC) to address the multi-disciplinary needs of patients in a time span and setting optimal for rapid diagnosis and management of issues that can be troublesome including depression, sleep disorders, memory loss and speech problems.

The comprehensive clinic is a (2) day visit to the Emory Brain Health Center. During the (2) days the patient and caregiver will meet with the following departments: Sleep medicine, Psychiatry, Speech Therapy, Occupational Therapy, Neuropsychology, Physical Therapy, Social Services and Movement Disorders Neurology.

Are you are interested in this (2) day evaluation? Please contact **Tammyjo Best, Program Coordinator at 404-712-6990.**

EMORY UNIVERSITY

Merrie Boone Comprehensive Care Clinic for Parkinson's

CONTACT
404-712-6990

EMORY UNIVERSITY

Jean and Paul Amos Parkinson's Disease and Movement Disorders Program

Make a Donation Today

2522

PATIENTS SERVED

Help Make A Difference.

WE ARE REACHING OUT TO

OUR COMMUNITY

PLEASE DONATE OR VOLUNTEER

Call or email to make your tax-deductible gift today.

Camille H. Sears, Director of Development
Phone (404) 727-9346
camille.sears@emory.edu

SUPPORT

404-712 7237

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Jean and Paul Amos Parkinson's Disease and Movement Disorders Program

Emory Brain Health Center
12 Executive Park Drive
Atlanta, Georgia 30329

www.neurology.emory.edu/movement