

# BECAUSE HOPE MATTERS

The Bi-monthly Newsletter of CurePSP



## 2011 RESEARCH SYMPOSIUM A SUCCESS

*Bruce Janele*  
 Director, Communications & Marketing

CurePSP’s International Research Symposium was held on November 17, 2011 in Arlington, Virginia, at the Crystal City Marriott.

The Symposium helps disseminate advances in the fields of PSP, CBD, and other atypical parkinsonisms. The event also highlights research performed by CurePSP grantees and is open to all researchers interested in clinical and basic studies of PSP, CBD, and related tauopathies. The Symposium also assists the Foundation’s Scientific Advisory Board in identifying work of exceptional promise, which may be considered for additional funding.

Presentations included:

Overview of the CurePSP Grants Program  
*Lawrence I. Golbe, MD, UMDNJ Robert Wood Johnson University Medical School*

Update on the CurePSP Brain Bank  
*Dennis W. Dickson, MD, Mayo Clinic Jacksonville*

Specific Triage Decisions for Distinct

Neurodegenerative Disease-associated Proteins that are Facilitated by DNAJ Proteins  
*Chad Dickey, PhD, University of South Florida*

Autophagic Modulation and Clearance of Tau Aggregates  
*W. Haung (Ho) Yu, PhD, Columbia University*

HSP-Peptide Complex-mediated Immunization in a Mouse Model of Tauopathy  
*Michael DeTure, PhD, Mayo Clinic Jacksonville*

Development of Activators for Puromycin-sensitive Aminopeptidase to Treat CBD  
*Stanislav L. Karsten, PhD, Los Angeles Biomedical Research Institute, NeuroInDx, Inc.*

Tau-mediated Effects on Microtubule Structure and Kinesin Translocation  
*Stuart C. Feinstein, PhD, University of California Santa Barbara*

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Foundation for PSP | CBD and Related Brain Diseases  
 because hope matters

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## AN ALTERNATE FORM OF THERAPY

Michael Plontz

Imagine a form of therapy that could be used by anyone with a variety of mental, physical, or emotional disabilities. It's not a drug and it has no side effects. It's always there for you whenever you need it. In fact it lives with you. It could be scaly, feathered or furry. We're talking about pet therapy, or, as it's sometimes referred to, "pet-facilitated therapy" or "animal-assisted therapy." The most commonly used pets for pet therapy are dogs, cats, horses, fish, birds and rabbits. Why are pets therapeutic?

Pets are alive. Being able to hold a pet or take care of another living creature provides much comfort. It can take the focus away from the illness or disability for a few moments.

Pets don't criticize or judge and they give love unconditionally. They accept us for who we are no matter what we do. They are very intuitive and can pick up on your emotions, and respond in an attentive manner.

Pets are trusting. We can learn trust from them and build trust in ourselves and others. Pets listen well no matter what you have to say. They don't interrupt or force their opinions on you.

Pets make us feel important and needed. Whether your day is good or bad, your pet can be the bright spot in your day. Their dependence on us for food, grooming, water and exercise makes us feel needed.

Pets can be very funny without even trying. They say that laughter is the best medicine. They make us talk "baby talk" and act sillier than we would normally. They like to play and enjoy it even more when we join in.

It may be too much for the caregiver to take on the responsibility of a pet along with everything else, but you should consider it. Not only might it be beneficial to your loved one, you may find that it's good therapy and stress relief for you, too. Consider adopting a pet from your local Humane Society. You'll feel even better for giving a needy pet a good home.

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Tau and its Pathology in Neurons Derived from Induced Pluripotent Stem Cells of FTDP-17T Patients with PSP-like Tau Pathology  
*Maria Grazia Spillantini, PhD, University of Cambridge*

Identification of Biomarkers via Comparative Proteomics of CBD and PSP Brains  
*Dennis W. Dickson, MD, Mayo Clinic Jacksonville*

The Role of the MAPT Locus in PSP and Parkinson's Disease  
*Nadine M. Melhem, PhD, University of Pittsburgh*

PSP Genetics: Progress, Plans, and Comparison to Other Neurodegenerative Disorders  
*Gerard Schellenberg, PhD, University of Pennsylvania*

The research topics discussed at our Symposium may be very difficult for most of us to understand or even comprehend, but what's important is that scientists researching atypical parkinsonisms are coming together and sharing their processes and findings.

Doing so facilitates the transfer of information, promotes future collaboration, and ultimately speeds up the long, arduous process of discovering an effective treatment or cure.

## SEARCHING FOR THE CAUSE: AN UPDATE ON THE GENETIC AND ENVIRONMENTAL RISK FACTORS STUDY

*Chris Cunningham and Whitney Rogers  
University of Louisville*

Dr. Irene Litvan and other collaborators at the institutions listed below have been busy recruiting and enrolling PSP patients, spouses, caregivers, and friends into the National Institutes of Health research study entitled, "Genetic and Environmental Risk Factors for PSP."

- Case Western Reserve (Cleveland, OH)
- University of Colorado (Denver, CO)
- Emory School of Medicine (Atlanta, GA)
- University of Maryland (Baltimore, MD)
- University of Alabama, Birmingham (Birmingham, AL)
- University of California, Los Angeles (Los Angeles, CA)
- University of Utah (Salt Lake City, UT)
- University of Toronto (Toronto, ON)
- University of Kansas (Kansas City, KS)

During the past 5 years, approximately 300 PSP patients have been enrolled. However, there is still a long way to go to reach the 500 PSP patient goal for the study. Thankfully, CurePSP has been a great help in spreading the word about the research study.

Study coordinators are actively seeking PSP patients and need to enroll 200 patients during the next year. If you are

interested in participating either as a patient, or as a healthy control for a friend or family member who has PSP, please contact the study coordinators. Your participation in this study will not preclude your involvement in any other PSP studies.

**The study is currently seeking subjects who have been diagnosed with PSP and meet the following criteria:**

- 40 years of age or older
- Able to participate in a telephone interview
- Can visit one of our screening sites
- Have no other major neurological disorders
- Can identify two healthy controls (a spouse or caregiver and an age and gender-matched, non-blood relative such as an in-law, friend or neighbor)

**Are you interested in helping advance the research into the causes of PSP as a Non-affected Control?**

PSP patients participating in the study are often unable to identify friends or spouses who can serve as their controls. Please contact the study coordinators if you would be willing to serve as a control for one of these individuals. Your time commitment would be minor, but the results will be invaluable for the study.

For more information, please contact the study coordinators at 1-866-PSP-0448 or visit [www.pspstudy.com](http://www.pspstudy.com).

## COMPASSIONATE ALLOWANCE UPDATE

*Bruce Janele*

*Director, Communications & Marketing*

In our last issue, we announced that the Social Security Administration (SSA) had added PSP, CBD, MSA, and ALS/PDC to its list of Compassionate Allowances (CAL) conditions. We've been working with the SSA to develop some more information.

CAL is a way of quickly identifying diseases and other medical conditions that meet SSA's disability standards, based on minimal objective medical information. Individuals diagnosed with these diseases will receive a decision on their disability claim in a matter of weeks, rather than the months it normally takes.

The links below provide general information regarding the Compassionate Allowances initiative and SSA's disability programs:

<http://www.ssa.gov/compassionateallowances/>

<http://www.ssa.gov/dibplan/index.htm>  
(Disability Planner)

### **Eligibility and Qualification**

In order to be eligible for disability benefits, you must meet the medical and non-medical criteria for the Social Security Disability Program (SSDI). For additional information about the SSDI program, please follow this link:

<http://ssa.gov/dibplan/dqualify.htm>

CurePSP will not be able to answer any questions regarding eligibility for disability benefits or qualification via Compassionate Allowances. Questions regarding these matters must be directed to the SSA.

### **Applying for Benefits**

Individuals can apply for disability benefits immediately. In the days leading up to December 10, 2011, disability examiners will be aware of new applications with PSP, CBD, MSA, and ALS/PDC and will be making these cases a priority. After December 10, 2011, SSA's computer systems will automatically identify applicants with these diseases and expedite them.

There are three ways to apply for disability benefits:

- Fill out and submit an online application:  
<http://ssa.gov/applyfordisability/>
- Call or visit your local Social Security office: <http://ssa.gov/locator/>

- Call the SSA's toll-free telephone number at 1-800-772-1213. If you are deaf or hard of hearing, you can call the SSA at TTY 1-800-325-0778.

If you have already applied for disability benefits, the Compassionate Allowances fast-tracking process should be used during the initial application or at the reconsideration, hearing or Appeals Council levels. It is advisable to also notify the disability examiner assigned to your claim that your condition has been selected for inclusion in the Compassionate Allowances program.

If you are planning to appeal a denial for disability benefits prior to December 10, 2011, you should include a statement on the reconsideration form that your condition has been selected for inclusion as a Compassionate Allowance. After December 10, 2011, your claim will be automatically identified and expedited.

After being approved for disability benefits and receiving benefits for 24 months, you will begin receiving Medicare benefits. SSA will automatically enroll you in Medicare. SSA begins "counting" the 24 month period based on the month you were first entitled to receive disability - not the month when you received your first check.

### **Retirement Benefits and Supplemental Security Income**

If you are 65 or older, you are eligible for Social Security retirement benefits, which are comparable to Social Security disability benefits. There is no reason to apply for disability benefits if you are in this classification. However, if you are receiving early retirement benefits (age 62-age 65), you should apply for SSDI because your benefits could increase and you may become eligible for Medicare before you turn 65.

You may also apply for Supplemental Security Income Program (SSI) benefits, which has different non-medical criteria, which are based on income. For additional information about the SSI program, please follow this link:

<http://ssa.gov/ssi>

CurePSP will continue to work with the Social Security Administration to provide the greatest possible amount of information regarding the inclusion of PSP, CBD, MSA, and ALS/PDC in the Compassionate Allowance program. Keep an eye out for more updates.

## MAKING A DIFFERENCE

*Kathleen Matarazzo Specca*

*VP, Development & Donor Relations*

I hope you and your loved ones had a wonderful holiday season! On behalf of CurePSP, I wish you a very Happy New Year.

Did you know that you can fundraise for CurePSP in the comfort of your home? With just a few clicks from your computer mouse, you can begin raising money to support all of our programs and services while enjoying shopping, surfing the internet, and much more. CurePSP has many options to choose from.

GoodSearch is a search engine toolbar that automatically raises money for CurePSP each and every time you use it to search for information. In addition, once you install the GoodSearch toolbar, you will also be able to enjoy other features such as GoodShop, GoodDining, and Amazon which raise additional funds.

eBay has a Giving Works program that allows you to designate a portion of proceeds to CurePSP for items you buy or sell.

Spiral Funds is another online shopping option which includes lots of stores to choose from and also provides CurePSP with donations and percentages from each item sold.

To learn more about these very easy fundraising options, please visit the home page of our website; scroll downward to the "Online Fundraising Tools" section, click on the link - "Gifts & Fundraising Page" and you will find step-by-step instructions to get started.

Did you also know that CurePSP has a special credit card with Capital One? CurePSP receives \$50 after your first purchase, 2% donation from gas and grocery purchases; 1% donation from all other purchases; and up to 10% of purchases made at select merchants. Sign up now to help CurePSP. Why not use this credit card for your purchases through GoodSearch, Spiral Funds, etc., and you'll double the amount you can raise for CurePSP!

To sign up for the CurePSP Capital One Credit Card, go to our website home page, scroll downward, and you will find this option on the left side, directly under the "Donate Your Vehicle" section. And, by the way, don't forget to check out this section as well to learn how to donate your car, truck, boat, van, RV, and even real estate to benefit CurePSP.

To learn more about named funds, special events, writing campaigns, and the online fundraising options above, please e-mail me at [specca@curepsp.org](mailto:specca@curepsp.org) or call 1-800-457-4777, extension 5672. I look forward to hearing from you.

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### MISSION

Increase awareness of progressive supranuclear palsy, corticobasal degeneration, and related brain diseases; fund research toward cure and prevention; educate healthcare professionals; and provide support, information and hope for affected persons and their families.

## SUPPORT GROUPS AND THE SHARING OF STORIES

*Bruce Janele*

*Director, Communications & Marketing*

CurePSP support groups encourage and organize activities that foster face-to-face communication and exchange of comfort and mutual benefit to caregivers, family, and friends of PSP, CBD, and MSA patients. As many areas of the country have no access to face-to-face support groups addressing atypical parkinsonisms, we are always in need of individuals willing to start a support group in their own local area. It is a simple process and CurePSP provides promotional support for new and existing groups. Please contact us if you're interested in helping!

CurePSP would like to thank its volunteer support group leaders and peer supporters for their outstanding dedication and commitment! Support group leaders are encouraged to send news and announcements (include photos when possible) about your groups to us for inclusion on our website and in upcoming newsletter issues.

Additionally, if you'd like to share a personal story about a loved one's battle with PSP, please send it to us, along with some photos.

## UPCOMING EVENTS OPPORTUNITIES FOR LEARNING AND SUPPORT

### WEBINARS

#### Understanding and Supporting Loved Ones with Aphasia

Ellayne Ganzfriend, MS, CCC-SLP  
*National Aphasia Association*  
Tuesday, January 10, 2012  
1:00pm - 2:00pm EST

#### PSP: Back to Basics

Amie Peterson, MD, Neurologist  
*Parkinson Center of Oregon, Oregon Health and Science University*  
Date TBD (rescheduled)

#### The Choking Problem and How to Help

Barbara Sonies, Speech & Language Pathologist  
*University of Maryland*  
Date TBD

### FAMILY CONFERENCES

#### 2012 Midwestern Family Conference

Dallas, Texas  
Spring 2012, Exact Date TBD

### SPECIAL EVENTS

#### 2nd Annual CurePSP 5K Fun Run

Saturday, January 14, 2012  
Enterprise, Florida  
8:00am  
Contact Renee Wilder at [wilderzoo@cfl.rr.com](mailto:wilderzoo@cfl.rr.com) for more information.

#### 8th Annual CurePSP Awareness & Memorial Walk

Saturday, March 31, 2012  
Mackle Park  
Marco Island, Florida  
10:30am Registration, 11:30am Walk  
Contact Cindy MacDonald at 239-353-3960 for more information.

### RESEARCH CONFERENCES

#### ADDF 6th Drug Discovery for Neurodegeneration Conference

February 12-14, 2012  
Princeton Club, New York, NY  
Educating scientists on the process of translating basic research into novel therapies.