curePSP
Foundation for PSP | CBD and Related Brain Diseases
because hope matters
30 E. PADONIA ROAD
SUITE 201
TIMONIUM, MD 21093
410-785-7004
TOLL FREE 1-800-457-4777
www.curepsp.org

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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.

NEW SUPPORT GROUPS ADDED

Alabama (Montgomery)
Group Leader: Ginger Darby, 334-201-1122, ginger_pridgen@yahoo.com

Colorado (Denver/Englewood)
Group Leader: Helenn Franzgrote, 303-789-9900, jhfranzgrote@comcast.net

South Carolina (Fort Mill)
Group Leader: Barbara Smith, 803-396-0963, scarolinagal67@comporium.net

We need new Support Group Leaders for the following areas: **Florida** (Southeast)
Virginia (Northern)
Canada (Eastern & Western)

We offer ongoing training and assistance to all our Support Group Leaders. Please contact Stan Viner at 1-800-457-4777 ext. 5668 for more information.

CALENDAR OF EVENTS OPPORTUNITIES FOR LEARNING AND SUPPORT

UPCOMING CONFERENCES

West Coast Family Conference
Hotel Angeleno
Los Angeles, CA
Saturday, May 7, 2011
10:00am – 4:00pm

East Coast Family Conference
Robert Wood Johnson University Hospital
New Brunswick, NJ
Saturday, June 4, 2011
10:00am – 4:00pm

These family conferences will feature speakers on topics related to medical updates, research, living with the diseases, and more. There is no fee to attend but space will be limited. Please register in advance.

RECENT WEBINARS

Topic: **Davunetide Research Update**
Presenter: Bruce H. Morimoto, PhD, *Vice President, Drug Development, Allon Therapeutics, Inc.*

Topic: **Elder Care Law – The Basics of Creating a Plan that Works for You**
Presenter: Kandace L. Scherr, Esq.

Visit www.psp.org/news-and-events/webinars.html for more information.

GIVE THE GIFT OF MUSIC AND SUPPORT RESEARCH FOR PSP

Dudley Moore Research Fund
Dudley Moore died in March of 2002, four years after being diagnosed with PSP. In honor of Dudley's long commitment to *Music For All Seasons,* MFAS created *The Dudley Moore Research Fund for PSP.* Visit www.dudleycd.com/charities.php to purchase Dudley's CDs, DVDs, and the book, *Letters from Dudley* – proceeds to help fund the continued research through CurePSP.

UPCOMING SPECIAL EVENTS

Exercise Your Mind (5K)
March 19, 2011 – Raleigh, North Carolina

CurePSP Awareness and Memorial Walk
April 2, 2011 – Marco Island, Florida

5K Run for PSP
May 7, 2011 – Plano, Texas

January / February 2011
Issue 2

BECAUSE HOPE MATTERS

The Bi-monthly Newsletter of CurePSP

Trish Caruana, MSW
Vice President, Programs & Education

Spring will soon be here and we are pleased to announce two very special events.

On May 7th from 10:00am – 4:00pm, CurePSP will host a West coast family conference in Los Angeles, CA. Our main presenter will be Dr. Yvette Bordelon, Assistant Professor at UCLA's Department of Neurology and a principal investigator in evaluating the safety and effectiveness of davunetide for the treatment of PSP. Other healthcare professionals will speak on topics including how best to manage symptoms, the impact of the diseases on the family, and unique perspectives on how to find meaning and joy.

On June 4th from 10:00am – 4:00pm, we will host an East coast family conference in New Brunswick, NJ, which is co-sponsored by the Robert Wood Johnson University Hospital. Dr. Larry Golbe, Professor of Neurology at the Robert Wood Johnson Medical School and Director of Research and Clinical Affairs for CurePSP, will be our main presenter. The topic areas will be similar to our West coast program.

The conferences are free of charge but you must register to attend. To register, please contact Stan Viner at 800-457-4777 or at viner@curepsp.org.

IN THIS ISSUE

Getting Educated P.2
Research Update P.2
Reflections P.3
European Research P.3
Making A Difference P.3
Calendar of Events P.4

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GETTING EDUCATED

Lawrence I. Golbe, MD
Director, Research and Clinical Affairs

PSP vs. MSA vs. CBD

What are the commonalities and differences among progressive supranuclear palsy (PSP), multiple system atrophy (MSA) and corticobasal degeneration (CBD)?

Each is relatively rare and none has a specific diagnostic test or known cause. Each starts gradually and results in severe disability and death after an average of about seven years — unless the very active research presently underway leads to new treatments.

They all cause general slowness and difficulty with balance, speech, eye movements and swallowing. With PSP, the eye movement problem and the difficulties organizing information are the worst. With MSA, there is usually the additional problem of low blood pressure and early appearance of bladder control problems and often, additional coordination difficulty resembling drunkenness. The balance problem is the least severe in CBD, but one side of the body is always far more affected than the other by difficulties in coordination and by excessive muscle stiffness.

RESEARCH UPDATE

ALLON INITIATES PSP TRIAL

Bruce H. Morimoto, PhD
Vice President, Drug Development
Allon Therapeutics Inc.

Allon Therapeutics Inc (Vancouver, B.C.) began enrolling patients in a Phase 2/3 clinical trial to evaluate the company's lead neuroprotective drug candidate, *davunetide*, as a potential treatment for PSP. *Davunetide* is developed from a natural brain factor called activity-dependent neuroprotective protein. In animal studies, *davunetide* has been shown to have beneficial effects on the protein, tau, which is thought to play a central role in the development of PSP.

The study's goal is to gather information on the safety of *davunetide* and its ability to slow the symptoms of PSP. The study drug will be taken twice a day as a nasal spray for 52 weeks. Half the patients will receive *davunetide* and the other will receive a placebo (a spray that looks like davunetide but does not contain any active drug). Neither the participant nor the study staff will know if *davunetide* or placebo is being given. Participants will undergo neurological examinations, tests of thinking and mood, blood tests and MRI scans. Some participants will also have detailed measurements of their eye movements taken. Participants will also be given the opportunity to provide a spinal fluid sample to help further evaluate the drug's effects. The trial will enroll approximately 300 patients in six countries, and is being led by Adam Boxer, MD, PhD from the University of California, San Francisco.

Regulatory agencies in the EU and US have granted *davunetide* orphan drug status for the treatment of PSP, recognizing the potential of *davunetide* in treating this rare disorder. The study will be conducted under a Special Protocol Assessment (SPA), granted by the United States Food and Drug Administration (FDA), which ensures that the study's design complies with FDA expectations. Allon believes that if this pivotal trial generates statistically significant and consistent data, *davunetide* will be considered by the FDA for approval in PSP. It is expected that data will be available for this study in about 2 years.

You can learn more about the *davunetide* study (and others) through the National Institute of Health (NIH) website. The site provides a great deal of information and is updated regularly.

Here's what to do:

- Point your internet browser to www.clinicaltrials.gov. A link to this site also appears on the homepage of the CurePSP website at www.curepsp.org.
- In the top right hand corner of the page, type in "Progressive Supranuclear Palsy" into the search bar and hit enter.
- The search results will yield multiple studies. The specific name of each study is listed, as is the condition (PSP) and the intervention type (drug name, biomarker, neuropsychological examination, etc).
- The status of the study will also be displayed, indicating whether it is active, recruiting, not yet recruiting, or completed.
- Locate the davunetide study, which is actively recruiting patients at this time.
- Study details will be listed, including how many more participants are needed or how long the study will last. A list of eligibility criteria will also appear (since most people have never participated in a research study, this page is especially valuable and should be read thoroughly).
- Near the bottom of the page, there is a section for contacts and locations; click the hyperlink below this information as it will list study site locations.
- Each study location will list contact information for the study coordinators.

REFLECTIONS

Richard Gordon Zyne, DMin
President – CEO

CurePSP lost a good friend recently. Robert P. Hanrahan passed away after his struggle with PSP. Bob dedicated his life to public service. He was a leader at Bloom Township High School in Illinois where he was recognized as the youngest member of the school's first ever Hall of Fame class. For the last 20 years, the Hanrahan Award has been given to the school's senior best suited for a public service career.

After college, Bob taught school and studied during the evenings. As a young assistant superintendent, he did the unthinkable: he defeated a two decade incumbent Cook County Superintendent of Schools in an election. His political career was launched. He ran successfully for Congress and made a great difference in people's lives, like the Lithuanian sailor he helped miraculously free from a communist prison. In the 1970's, Bob served as Deputy Secretary of Education under President Gerald Ford.

As a member of the CurePSP Major Gifts Committee, Bob was responsible for developing contacts and relationships that led to gifts of over $3 million for research, creating fifteen new research grants that are currently being conducted for the benefit of people with PSP and CBD.

Bob leaves his wife of 53 years, Barbara, three sons, and nine grandchildren. We thank him for his service to his country and to those suffering with PSP, CBD and related brain diseases.

EUROPEAN RESEARCH

Noscira Pharmaceuticals
Barcelona, Spain

The TAUROS study is investigating Noscira's drug called tideglusib, a medication also been investigated for Alzheimers disease. The drug is still at early stages in clinical trials and so it is not available in the market.

Tideglusib inhibits an enzyme, GSK-3 which may slow down the neurodegenerative process in PSP. Tideglusib has obtained orphan drug designation for PSP, from both the US and EU authorities.

The TAUROS study is a randomized trial, with some patients getting a placebo and some getting tideglusib. The study included 146 patients at 24 centers in Europe and the US. The study is still ongoing, but recruitment is closed. Patients with possible or probable PSP first underwent a screening process to see if they were eligible to participate in the study. Those who were eligible were randomly assigned to receive a daily oral does of tideglusib or a placebo for one year. At the end of the study they will undergo an 8-week follow-up period without medication. The primary objective of the study is to evaluate the overall clinical change assessed by the PSP Rating Scale (Golbe & Ohman-Strickland). The secondary objective is to evaluate the safety and tolerability of the compound. Other objectives include evaluating clinical changes in motor function, cognition, behavior, activities of daily living and quality of life. Noscira expects to have TAUROS study results by the end of 2011.

Noscira is appreciative to all PSP patients, families and investigators for collaborating in the TAUROS trial.

MAKING A DIFFERENCE

Kathleen Matarazzo Speca
Vice President, Development & Public Relations

Special Events combined with our direct mail appeals are the financial lifeline for CurePSP. These efforts support our programs, which help families, fund research, educate professionals, and create community awareness.

Below are fundraising events for the months to follow this newsletter:

- ***Exercise Your Mind (5K)***
  March 19, 2011 – Raleigh, North Carolina
- ***CurePSP Awareness and Memorial Walk***
  April 2, 2011 – Marco Island, Florida
- ***5K Run for PSP***
  May 7, 2011 – Plano, Texas

For additional special event information, please visit www.curepsp.org, select "News and Events" and click on Special Events.

Community based marathons are a great way to raise funds and create community awareness. Since they are not designed for any specific charity, participants can raise funds for the charity of their choice. CurePSP can provide runners with a special donation page, email blasts, and more. If you're not a runner, but enjoy walking, many community 5K runs also offer a one mile fun walk. Please consider participating to help raise awareness and funds for CurePSP.

If you would like to organize an event in your area, or if you don't have time to plan an event but want to do something to help CurePSP with these projects, please contact me – speca@curepsp.org or call 1-800-457-4777, ext. 5672.