I am honored to have been appointed President of CurePSP, following the retirement of Richard Gordon Zyne, MS, DMin. In his 10 years with the organization, Dr. Zyne played a leading role in building CurePSP from its roots as an association of families in the Baltimore area who had been affected by PSP into one of the leading organizations in the fight against neurodegenerative disease.

These are exciting times in neurodegenerative disease research. Scientists supported by CurePSP and other organizations are making encouraging strides in genetics, biomarkers, clinical diagnosis, the mechanisms of protein misfolding, cellular biology, drug discovery, and palliative treatments. From a disease that was largely ignored until the 1980s, neurodegeneration is now one of the great healthcare crusades of the 21st century.

In particular, PSP is seen by academic researchers and the pharmaceutical industry as a “fulcrum” disease, providing leverage for the investment of research resources in the discovery of causation and cure for other, more common, neurodegenerative diseases. “Big pharma” is now paying attention to the entire category of rare neurodegenerative diseases because of the potential for the development of blockbuster drugs that will open up a huge global market of patients with the more common Alzheimer’s, Parkinson’s, and ALS (amyotrophic lateral sclerosis) diseases. CurePSP, as the leading organization focusing on PSP and related atypical Parkinsonian syndromes like CBD, is perfectly positioned to take a leading role in the fight against neurodegeneration.

Going forward, CurePSP will have a focused, three-pronged approach. We will be the leader among several organizations involved in rare neurodegenerative disease research.

First, we will create broad awareness of these devastating conditions under the banner of “Prime of Life” diseases that often strike during a person’s most productive and creative years when he or she has family and work responsibilities and is active and engaged. The recent and unfortunate passing of the talented contemporary jazz guitarist Jeff Golub at age 59 from PSP is an example of the tragic impact of these diseases. This effort will be spearheaded by Bruce Janele, our Director of Communications and Public Awareness, an experienced marketing professional. I will support Bruce with my long experience in brand strategy, tactical marketing, and design.

Second, we will take advantage of increased awareness, cultural relevance, and emotional poignancy to leverage the spectacular contributions of our dedicated donor base to tap into additional...
Third, we will continue to improve our already category-leading efforts in patient, family, and caregiver support, as well as the education of healthcare professionals. We will be expanding these efforts globally through affiliations with existing national organizations and “franchising” of the CurePSP brand. Trish Caruana, MSW, our talented and peripatetic Vice President of Programs and Education, is now negotiating the relationship with our Canadian affiliate to create an integrated North American front.

Along with other forward-thinking philanthropic organizations, CurePSP is starting to apply some of the best practices in the private sector to its work – often termed “venture philanthropy.” These will include:

- **Willingness to try new approaches.** For example, we are investing $3 million toward research in drug discovery.

- **Focus on metrics.** We will evaluate research grants with a keen eye toward measuring ongoing progress and results.

- **Investing in human capital.** CurePSP is now actively recruiting a high-level executive in charge of scientific affairs and a social media communications assistant.

- **Collaboration and cooperation to achieve goals.** We are partnering with leaders in the public and private sectors including the Association for Frontotemporal Degeneration (AFTD), the Tau Consortium, the Bluefield Project, and the University of California, San Francisco to build a patient registry to ensure the fast tracking of clinical trials. Our collaboration extends to Johns Hopkins University, the Mayo Clinic, and the University of Pennsylvania’s Perelman School of Medicine. In the private sector, we are collaborating with pharmaceutical companies like Bristol-Myers Squibb. As with business, we will look at synergies that lead to success.

In building awareness, relevance and support for CurePSP’s work, we will tailor our communication to the specific interests and priorities of each of our audiences. This doesn’t mean we are “all things to all people.” Quite the contrary - we will have a clear, focused platform around research, patient and caregiver support, and education and awareness that will create interest and ignite passion with all our constituencies. For example:

- **Scientists:** I want to be on the cutting edge of neurodegenerative disease research.

- **Doctors:** I need to know more about these diseases so I can be more effective in my practice.

- **Foundations, trusts, and donors:** I want to invest where it will have the most impact and generate the most favorable outcomes.

- **Biotech and pharma:** I see potentially a big market and profit opportunity in PSP research. Government designation of PSP as a rare “orphan disease” provides several advantages including fast-track approvals and various subsidies for clinical trials. PSP research provides an ideal gateway (a “fulcrum”) for discoveries that may lead to treatment and cure of other neurodegenerative diseases. PSP provides a patient pool in early disease stages for clinical trials.

- **Patients, families, caregivers:** CurePSP is the only organization that caters specifically to my needs.

- **The general public:** I have not heard about these Prime of Life diseases and I want to know more.

In creating awareness for the Prime of Life neurodegenerative diseases, we will engage the best creative talent and employ the latest communication approaches to effectively reach a broad audience. These will include public service advertising, our website, social media, public relations, and increased support for local groups and events. Our goal is to create awareness and relevance for Prime of Life diseases equivalent to that of Alzheimer’s disease, Parkinson’s disease, and ALS. Influencing public opinion takes time and this will not occur entirely in 2015 by any means, but we are “setting the wheels in motion” in this direction. Having clear, long-term goals will mean that donor funds are used most efficiently and effectively.

On the research front, our Scientific Advisory Board (SAB), ably led by Lawrence Golbe, MD, of Rutgers Robert Wood Johnson Medical School, will be evaluating an increased flow of research proposals generated by this increased awareness and leadership of CurePSP. Dr. Golbe, who is one of the world’s leading PSP clinicians, and the SAB will be evaluating proposals to ensure that donor funds are most effectively employed. We will promote research results through our public awareness efforts to generate increased attention for CurePSP as the leader in research into Prime of Life neurodegenerative diseases.

All in all, we are entering the most exciting time to be involved in neurodegeneration research, education, and care. We are at the dawn of an era of great discoveries that have the potential to improve the lives of millions of people around the world. CurePSP is positioned to be a leader in the quest to eliminate one of the great scourges of humankind.
Today I am writing about living with a terminal illness, moving to 'acceptance' as soon as possible, and living each day to the fullest. This article also includes practical information about what worked for me, when I was newly diagnosed with a terminal illness.

I have multiple system atrophy (MSA), a rare neurological disorder, a shrinking of the brain; the symptoms are very similar to progressive supranuclear palsy (PSP), but the disease is different. March is System Atrophy Awareness Month and I'd like to spread awareness about this rare disorder. I'm 63 and as of March, I've been diagnosed with MSA for seven years. But I've had symptoms for over ten years and, like many of us with MSA and PSP, it took several years and many doctors to get an accurate diagnosis.

Benjamin Franklin humorously said, "In this world nothing can be said to be certain, except death and taxes." We all die. Those of us who are diagnosed as terminally ill perhaps die sooner than we would have thought we would, and we likely know what we will die of, but death is part of life. None of us escape it.

So, when diagnosed with a terminal illness, I made sure all my legal documents were in order (or I got the ones that were missing - all adults should do this anyway): wills and advance directives, Five Wishes, and Physician Orders for Life Sustaining Treatment (POLST). Make sure your documents address strokes and dementia, LGBT concerns, sectarian hospitals, or anything else that is important to you. Talk to family members or close friends about your end of life wishes: disposal, funeral/memorial, and brain or other organ donation.

Many life insurance companies sell a product called "guaranteed-issue," meaning they will issue a policy regardless of diagnosis. Thus, if you have loved ones, I recommend buying all the life insurance you can afford right now.

I read books that sensitively handle these tough topics. Two books I have read and highly recommend are Hard Choices for Loving People by Hank Dunn, and Handbook for Mortals by Joanne Lynn and Janice Lynch Schuster. Both books can easily be found online.

In 1969, Dr. Elisabeth Kübler-Ross published her now classic work, On Death and Dying. In it, after interviewing hundreds of terminally ill patients, she said that people seem to pass through five stages: denial, anger, bargaining, depression, and finally (hopefully) acceptance. Not everyone gets to acceptance.

Then, in 1978, Daniel Levinson published his book, The Seasons of a Man's Life, his study of adult development and the tasks we all go through as adults.

I'd like to combine the two studies for those of us with a terminal illness. I think our task is to move to the acceptance stage as soon as possible.

Anger is a waste of our precious time and should be moved through as quickly as possible, while doing as little damage as possible. Know how especially hard a terminal illness is on spouses and intimate partners or friends. Don't burden them further with your complaints. Talk at a support group, or other appropriate outlet, about how your disease sucks or how losing things slowly is a bummer.

Also, don’t waste time, money, or energy trying to find a cause or cure for your disease. Lots of researchers have tried over the last 50 years, studying thousands of people with little success. This is not to say that researchers won’t find a cure eventually. It will just take a long time and your resources would be better spent focusing on other things like improving your quality of life. That being said, I’ve decided to be a donor, because for me, it is one way I can contribute to research and an eventual cure. Well meaning friends may suggest a special diet, or a doctor in California they’ve seen on the web, or oils, or vitamins, or, or, or. Especially beware of costly stem cell replacement therapy; it is being studied, but it is not approved for treatment anywhere in the US, and never have the results been scientifically shown to cure neurologic disorders (yet).

Do join a support group; I participate in two: a monthly, online support group, and one in person in Portland, Oregon (also monthly). Even if you don’t speak much, it will likely be helpful to you to hear others who are living with a chronic and terminal illness.

You have no choice about getting your disease, but you can and will determine how you respond to it. Will you be gracious or angry in giving up your job, driving, and your independence?

Shortly before writing, "I can do all things through Him who strengthens me," Paul wrote, "I have learned to be content with whatever I have."

This is our goal - to be content. That's acceptance, I think.

Eleanor Roosevelt said, "Yesterday is history, tomorrow is a mystery, and today is a gift; that's why they call it the present."

So I focus on living each day to the fullest. Do what you enjoy and what you can do safely.

I've been enjoying watching former episodes of Boston Legal (thank you, Netflix). On a recent episode about assisted suicide, Denny Crane (played by William Shatner), reflective of his own life says, "I don’t have much longer." His good friend, Alan Shore (played by James Spader) advises him, "Until then, live big, my friend."

Good advice.
List of Clinical Trials for PSP, CBD and MSA, as of January 2015

**Tau Imaging in Subjects with PSP, CBD and Healthy Volunteers**

ClinicalTrials.gov Identifier: NCT02167594  
**Group(s):** PSP, CBD  
**Purpose:** to evaluate the safety and efficacy of drugs florbetapir F 18 and 18F-AV-1451 via IV injection.  
**Location(s):** Birmingham, AL; Lo Jolla, CA; New Haven, CT; Philadelphia, PA  
**Contact:** Avid Clinical Operations, 215-298-0700, clinicaloperations@avidrp.com

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**4 Repeat Tauopathy Neuroimaging Initiative (4RTNI)**

ClinicalTrials.gov Identifier: NCT01804452  
**Group(s):** PSP, CBD  
**Purpose:** to identify the best methods of analysis (including eye movements, imaging, and behavioral measures) for tracking PSP and CBD over time.  
**Location(s):** San Francisco, CA  
**Contact:** Dan N. Luong, BS, 415-476-9578, pluong@memory.ucsf.edu

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**Safety Study of TPI-287 to Treat CBS and PSP (TPI-287-4RT)**

ClinicalTrials.gov Identifier: NCT02133846  
**Group(s):** PSP, CBD  
**Purpose:** to determine the safety and tolerability of intravenous infusions of TPI 287 administered once every 3 weeks for 9 weeks (for a total of 4 infusions) in patients with CBD and PSP.  
**Location(s):** Birmingham, AL; San Francisco, CA  
**Contact:** Emma Hare, BA, CCRP, 415-476-8333, ehare@memory.ucsf.edu; Mary Koestler, RN, PhD, CCRC, 415-476-0661, mkoestler@memory.ucsf.edu

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**Evaluation of [18F]MNI-777 PET as a Marker of Tau Pathology in Subjects with Tauopathies Compared to Healthy Subjects**

ClinicalTrials.gov Identifier: NCT02103894  
**Group(s):** PSP  
**Purpose:** to assess PET imaging as a tool to detect tau pathology in the brain of individuals who carry a clinical diagnosis of a tauopathy, including PSP.  
**Location(s):** New Haven, CT  
**Contact:** Danna Jennings, MD, 203-401-4300, djennings@mnimaging.com

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**MRI Study of Brain Activity in Healthy Adults and Individuals with Parkinsonism and Rapid Eye Movement Disorder**

ClinicalTrials.gov Identifier: NCT01547481  
**Group(s):** PSP, Any Form of Parkinsonism  
**Purpose:** to help better understand the patterns and timing of nerve degeneration relatively early in the disease, and how this affects symptoms and progression.  
**Location(s):** Ann Arbor, MI  
**Contact:** Arijit K. Bhaumik, BA, CCRP, 734-936-8281, arijit@umich.edu; dna Rose, PhD, RN, MSW, BC, 734-936-7359, ednarose@umich.edu

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**PET Imaging Study of Neurochemical and Autonomic Disorders in MSA**

ClinicalTrials.gov Identifier: NCT02035761  
**Group(s):** MSA  
**Purpose:** to help better understand the patterns and timing of nerve degeneration relatively early in the disease, and how this affects symptoms and progression.  
**Location(s):** New York, NY  
**Contact:** Jose Martinez, MA, 212-263-7225, jose.martinez@nyumc.org

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**Treatment of Parkinson Disease and Multiple System Atrophy Using Intranasal Insulin**

ClinicalTrials.gov Identifier: NCT02064166  
**Group(s):** MSA  
**Purpose:** to assess the efficacy of intranasal insulin (INI) in treatment of cognitive abnormalities in both PD and MSA.  
**Location(s):** Worcester, MA  
**Contact:** Peter Novak, MD, 508-334-2527, novakp@ummhc.org; Paula Ravin, MD, 508-334-2527, ravinp@ummhc.org

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**The Phenotype and Natural History of Primary Autonomic Disorders**

ClinicalTrials.gov Identifier: NCT01799915  
**Group(s):** MSA  
**Purpose:** to characterize the clinical features and biological markers of the different types of primary autonomic disorders and better understand how these disorders evolve over time.  
**Location(s):** New York, NY  
**Contact:** Jose Martinez, MA, 212-263-7225, jose.martinez@nyumc.org

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**Water and Sudafed in Autonomic Failure**

ClinicalTrials.gov Identifier: NCT02149901  
**Group(s):** MSA  
**Purpose:** to determine whether water ingestion potentiates the pressor response to pseudoephedrine in patients with primary disorders of autonomic failure.  
**Location(s):** Nashville, TN  
**Contact:** Bonnie K. Black, BSN, CNP, adc.research@vanderbilt.edu
Fatigue can be a debilitating symptom for both patients with PSP and their caregivers. Fatigue often becomes a cycle of lethargy, inactivity and frustration. Our daily habits and routines, as well as societal values on productivity can influence our patterns of rest and activity. It is important for both patient and caregiver to take optimum care and work toward awareness of the need for stimulation and rest in daily life. Each of us is unique in what can be depleting and recharging for us. Becoming mindful of creating a balanced schedule, pacing and planning your day, saving energy when you can, and practicing wellness strategies can help decrease and prevent extreme fatigue and leave more energy for doing the things you enjoy.

The Importance of Rest

Rest can be used as a proactive, defensive strategy to combat fatigue. There are many ways of resting—listening to music, doing quiet hobbies, meditating, sitting quietly and napping. Planning short, frequent rest breaks into your daily routine can help offset bouts of severe fatigue. It is important to rest before you become fatigued and break up heavy and long duration tasks with 15-30 minute rest breaks. The goal of taking routine rest breaks is to help you feel better overall and become more productive. Experiment with what types of rest at what times of day benefit you most—and make it a daily habit!

Pace, Plan and Prioritize Your Day

We need a balance in our lives between work tasks, self-care routines and leisure activities. Try to plan your day to create a balanced schedule to make the most of your energy. Using a daily planner, smart phone or simple list can help organize and frame your day. Keep expectations realistic and note patterns of ‘biting off more than you can chew’, by trying to do too many activities in a day. If you are preparing for a special outing or event, avoid any heavy tasks or chores that day. Rest up in the days ahead to save up energy for enjoying time with loved ones or participating in a social activity. Try to keep in mind what is the most important, highest priority for you personally.

Conserve Your Energy by Modifying Daily Tasks and Routines

The more energy a task requires to perform, the more you should consider ways to modify how you perform the task to save your energy. It can be surprising how demanding our daily routines can be, especially our self-care activities. Simply sitting on a shower chair, using a hand held shower and long handled bath sponge, and having all items within reach can save energy in bathing for other tasks. Consider breaking up the routine of showering, grooming, and dressing before leaving for work or an appointment in the morning by showering the night before and having clothing selected and organized for dressing. For the caregiver, breaking up these tasks
It’s not for everyone, I know, but it has given me a sense of helping caregivers, because often caregivers attend both meetings. The support group we attended was wonderful, but there were concerns that I didn’t feel comfortable discussing in front of our loved ones (e.g. bowel and bladder problems, etc.), so I asked other caregivers if they would also like to meet separately. The answer was a resounding yes, so I started the group for caregivers other than those who are patients. The group has been a rewarding and healing experience for me, and the caregivers often express their appreciation for our support.

What made you decide to become a Support Group Leader and what has been the most valuable aspect about being a Support Group Leader?

The support group we attended was wonderful, but there were concerns that I didn’t feel comfortable discussing in front of our loved ones (e.g. bowel and bladder problems, etc.), so I asked other caregivers if they would also like to meet separately. The answer was a resounding yes, so I started the group for caregivers other than those who are patients. The group has been a rewarding and healing experience for me, and the caregivers often express their appreciation for our support.

I feel as though I’m providing a venue where caregivers can “tell it like it is” and we all understand — they can ask questions, get caregiving tips, share information, and know that they are not alone as they care for their loved ones. I have made some wonderful friends, some of them still caring for their loved ones and some with loved ones who have passed on (my husband died in April 2011, a few months after I started the group). It has been a rewarding and healing experience for me, and the caregivers often express their appreciation for our group.

How long have you been volunteering?

I’m starting my fifth year!

Patricia Hagan serves as the facilitator for a “caregivers only” support group in San Diego, California for those dealing with atypical Parkinsonian disorders such as PSP, CBD, MSA, OPCA, SND and SDS.

Who in your life has been affected by PSP, CBD or MSA and how did you find out about our organization?

I first learned about PSP when my wonderful husband of only 5 years (2nd marriage) was diagnosed by a neuro-opthalmologist. We were referred to a movement disorder specialist and she was the one who told us about PSP.org and about a newly established support group in our area.

What made you decide to become a Support Group Leader and what has been the most valuable aspect about being a Support Group Leader?

The support group we attended was wonderful, but there were concerns that I didn’t feel comfortable discussing in front of our loved ones (e.g. bowel and bladder problems, etc.), so I asked other caregivers if they would also like to meet separately. The answer was a resounding yes, so I started the group for caregivers other than those who are patients. The group has been a rewarding and healing experience for me, and the caregivers often express their appreciation for our group.

How long have you been volunteering?

I’m starting my fifth year!

Patricia’s Support Group

Information: Only for caregivers dealing with Atypical Parkinsonian Disorders like PSP, CBD, MSA, OPCA, SND, SDS
Location: Holy Angels Byzantine Catholic Church, 2235 Galahad Road, San Diego, CA 92123
Meeting Time(s): On the following Wednesdays from 11:00am - 1:00pm: Apr. 30, July 2, Sep. 3, Nov. 5
Facilitators: Patricia Hagan, 619-223-1645 or 619-222-5107, pkhagan@cox.net

Volunteer Spotlight

PATRICIA HAGAN
SUPPORT GROUP FACILITATOR

Nourish Your Body, Mind, and Spirit

Proper nutrition, activity/exercise, stress management, and fostering a support network are crucial to your overall well-being and can help decrease and combat fatigue. Fueling your body with a balanced diet of fruits and vegetables, lean protein, healthy fats and whole grains helps to sustain energy levels throughout the day. Try eating small, more frequent meals/snacks and avoid excessive sugar and caffeine, which can contribute to fatigue. Discuss options for exercise/activity with your physician to see what is safe for you. Many seated exercise programs are available, including Tai Chi, which can help reduce stress as well. Board games, crafts and card games provide cognitive exercise and interaction with others—think of any you used to enjoy in the past. Mindfulness, meditation, and prayer can help to reduce stress and anxiety which can contribute to fatigue. Attend a local support group, talk with a friend, or participate in social activities to create an outlet for feelings and foster a sense of belonging. Communicate with friends and family about your fatigue and let them know how they can help you—they probably wish you would ask!

Be Patient with Yourself

Unfortunately, there is no prescribed approach to diminish fatigue for everyone. Each individual must experiment and be open to discovering new ways of approaching daily tasks and routines. We are creatures of habit, and making changes to our routines can be difficult. Energy and fatigue levels can vary day to day, and flexibility is needed to establish daily rest and activity patterns to meet fluctuating needs. Working to manage fatigue can promote improved self-awareness, greater attention to wellness, and promote communication with loved ones to foster support throughout the process of living with PSP.

References


About the Author

Julia Wood MOT, OTR/L is the occupational therapist at the Dan Aaron Parkinson’s Rehabilitation Center at Pennsylvania Hospital in Philadelphia, Pennsylvania.
On October 17, 2014 at the Mount Washington Conference Center in Baltimore, Maryland, CurePSP held its Milestones and Horizons event to honor the work of John C. Steele, MD, FRCP. In 1964, exactly 50 years ago, Drs. John C. Steele, J. Clifford Richardson and Jerzy Oszewski first discovered progressive supranuclear palsy. Dr. Steele’s influential work served as the springboard for the founding CurePSP 26 years later, in 1990. Since then, Dr. Steele’s support and guidance through the last 24 years, along with much dedication by many other talented professionals, has helped CurePSP flourish as a leader in patient support and neurodegenerative disease research. With his visionary contributions to the world of medicine, Dr. Steele, who also continues to serve as CurePSP’s Honorary Board Chairman, has strengthened the Foundation’s mission to help those suffering with the cruel disease.

Serving as the evening’s Presenting Sponsor, the Light of Day Foundation, which utilizes the power of music to raise money and awareness in its battle to defeat Parkinson’s and related neurodegenerative diseases such as ALS and PSP, announced the donation of more than $80,000 to CurePSP via a hugely successful matching gift campaign. The event was also sponsored by Johns Hopkins Medicine, C2N Diagnostics, and six other dedicated organizations.

Dr. John Trojanowski, a Penn Medicine researcher who, along with research partner and wife Dr. Virginia Lee, is currently working on a tau immune therapy for PSP, discussed the current state of neurodegenerative disease research. Notable tributes to Dr. Steele were made by CurePSP’s co-founder Joanne Armstrong, Cardiff University researcher Dr. Huw Morris, and former CurePSP board member Dr. Murray Goldstein. Among the numerous highlights of the evening was special guest and Pulitzer Prize-winning author Jonathan Weiner, who presented a video interview with legendary neurologist Dr. Oliver Sacks about the history of PSP and his friendship with Dr. Steele. The evening concluded with the presentation of a commemorative plaque honoring Dr. Steele, as well as a painting created by former CurePSP President-CEO Dr. Richard Zyne with Dr. Steele in mind.

About John C. Steele, MD, FRCP (pictured far right, with son and grandson)

Dr. Steele’s father and grandfather were physicians who sparked his interest in medicine. After preparation at the University of Toronto, he enrolled in their medical school in 1952.

Neurologist Clifford Richardson encouraged him to pursue neurology, and in 1965 he completed the residency program at Toronto General Hospital. In 1968, after spending a year in Thailand as an instructor of neurology at the Prasat Neurological Institute, Dr. Steele returned to Toronto to be a staff member at the Hospital for Sick Children.

After a visit to Micronesia in western Oceania in 1972, Dr. Steele agreed to join the US Trust Territory of the Pacific Islands as a part of a new and innovative health service for the region. By 1982, he and his colleagues had established a referral hospital and medical education center there, in the center of Micronesia. Upon completing the ten year health development project, he moved to Guam to become the main neurologist at the US Naval Hospital and Medical Director of a VA clinic.

Dr. Steele began new observations of Parkinsonism, identifying the prevalence of ALS/Parkinson-dementia complex (ALS/PDC) and confirming its clinical similarities to PSP. Dr. Steele remains optimistic that ALS/PDC of Guam can still be understood and can provide understandings of PSP and related neurodegenerative diseases such as Alzheimer’s disease, Parkinson’s disease and ALS.
Our mission
Awareness, education, care, and cure for devastating Prime of Life neurodegenerative diseases.

The CurePSP Newsletter is made possible through the generous support of the Joanne Armstrong and Richard A. Janney Fund for Patient Support and Professional Medical Education.

Upcoming Events

**SPECIAL EVENTS**

11th Annual CurePSP Awareness & Memorial Walk - Cindy MacDonald
Saturday, March 14, 2015
Mackle Park
Marco Island, Florida
239-353-3960

1st Annual Southern Illinois CurePSP 5K Run for Hope
Saturday, May 16, 2015
Carterville, Illinois
(see curepsp.org for more details)

**NEW SUPPORT GROUPS**

North Carolina - Raleigh/Durham/Chapel Hill
Information: Patients, Caregivers and anyone affected by PSP
Location: UNC Center for Rehabilitative Care, 1807 N. Fordham Blvd, Chapel Hill, NC 27514
Meeting Time(s): April 1, 2015 at 1:00pm – 3:00pm, 1st Wednesday of every month thereafter
Facilitator: Jocelyne Gervais, 919-260-6812, jrgassociatesllc@gmail.com

Missouri - St. Louis
Information: For patients, caregivers, and anyone affected by PSP
Location: St. Louis Altenheim, 5408 South Broadway, St. Louis, MO 63111
Meeting Time(s): 4th Friday of every month at 11:00am
Facilitator: Beth Evans, 314-732-3433, notelizabethevans@gmail.com

**CONFERENCES**

CurePSP Canadian Family Conference
Saturday, June 13, 2015
Southway Hotel
Ottawa, Ontario