Winning the battle against neurodegeneration is the great medical crusade of the 21st century. With the progress that has been made against infectious diseases, cancer, and heart disease, attention to neurodegenerative diseases will become more prevalent. And CurePSP will be on the front lines of this fight.

We have repositioned CurePSP around a spectrum of related conditions called prime of life neurodegeneration, which include progressive supranuclear palsy (PSP), corticobasal degeneration (CBD), multiple system atrophy (MSA), frontotemporal dementia (FTD), amyotrophic lateral sclerosis (ALS), and chronic traumatic encephalopathy (CTE). While these diseases are relatively rare, afflicting an estimated 150,000 people, they most often strike during a person’s most productive years when she or he may have family, a job and a rewarding, active life. According to the National Institutes of Health (NIH), half of neurodegeneration prior to age 65 involves prime of life diseases (although Alzheimer’s disease is far more prevalent in the population as a whole).

CurePSP’s mission is focused on three areas: supporting patients and families and educating doctors and other healthcare professionals; creating broad awareness around prime of life neurodegeneration; and funding and supporting scientific research (“care, consciousness, cure”).

“Tau is the how” in neurodegeneration research
Current research suggests that the range of neurodegenerative diseases have similar causes and that the tau protein plays a key role in most of them, including Alzheimer’s disease. PSP in particular is a preferred target for study because it is a pure tauopathy (involving only the tau protein) and has a clearly identified patient population for clinical trials. Research is now starting to move from animal models and “disease in a dish” (in vitro testing) to preliminary clinical trials. Pharmaceutical companies are very interested in PSP because it may hold the key to unlocking the secrets of all neurodegeneration and lead to a huge market for new drugs.

CurePSP is staged to play a leading role in the study of CTE, which is a tauopathy that affects individuals, particularly some...
athletes, who have suffered repeated concussions. There is little data on patient populations or research findings on the disease. However, CTE offers a rich opportunity for the study of the causation and progression of neurodegeneration and presents a high-profile opportunity for CurePSP.

On the research front, CurePSP will continue to evaluate and fund, with your help, investigator-initiated grants. These grants are proposals submitted for a variety of studies that originate with scientists. This effort is being directed by Dr. Alex Klein, our new Vice President - Scientific Affairs, in collaboration with Dr. Lawrence Golde, head of our Scientific Advisory Board (SAB). Alex comes to CurePSP from Germany, where he most recently was involved in the administration of scientific grants for the European Union (see profile in an upcoming issue).

We are also presenting a menu of directed research opportunities to large individual donors and foundations around genetics, stem cells and tau immune therapies that will require major funding over a period of years. CurePSP's International Research Symposium to be held November 5-7 in La Jolla, California, will bring together investigators to present their latest research and pharmaceutical company executives interested in exploring opportunities for clinical trials.

To serve the mission of finding treatment and cure for neurodegeneration and create a new source of funding for the foundation’s work, we have begun the Patient Engagement Program (PEP) as a separately incorporated entity. PEP will establish relationships with pharmaceutical companies to help them recruit subjects (“cohorts”) for their trials; to guide them through the process; and to educate neurologists and affiliated healthcare professionals about these clinical trials and their benefits. All profits from PEP will flow back to CurePSP to further its work.

Support for patients and families differentiates CurePSP

CurePSP is strengthening its commitment to patients, families and care partners to help ease the burden of these terrible afflictions. We are the first “port in the storm” for families struck with neurodegenerative diseases as resources allow. We are the initial place to turn for education, guidance and fellowship of those who see support of CurePSP as a productive investment.

None of this work would be possible without the support of our generous and loyal donors. We are confident that there is no better place to invest money than in the work of CurePSP. None of this work would be possible without the support of our generous and loyal donors. We are confident that there is no better place to invest money than in the work of CurePSP.

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A. People with PSP often report difficulty getting up out of a chair, specifically that it takes them multiple attempts and/or that they will fall backwards in the chair when trying to stand up. In therapy, the task is broken down into parts. Each part is practiced with high repetition and these parts are then combined in order to make a successful transfer from sit to stand.

1. The first step is to evaluate where you are positioned in the chair. If your hips are to the back of the chair you need to position them towards the front of the chair. Utilize the arm rests or place hands on the seat of the chair if you do not have arm rests. Coordinate the movement from back of chair to front of chair by saying in your head or out loud, “1,2,3 push.” This will coordinate your efforts best in order to scoot yourself to the edge of the chair in one attempt. Scooting in a chair is often practiced in therapy and can easily be practiced in the home. Try 10 repetitions of using your arms to scoot your hips forward and backwards in the chair.

2. Once your hips have been positioned to the edge of chair evaluate where your feet are positioned. Feet should be placed underneath your knees.

3. Place your hands in a supportive position, either on arms rests or on the chair seat.

4. Consider the phrase often used by therapists – “nose over toes” - in order to remind yourself to reposition your trunk forward. This is necessary in order to shift your body’s weight over your feet. People with PSP will often push their body straight upwards, which may result in falling back into the chair. If you are aware to lean your weight forward, your body weight will come over your feet and you can then use your legs to come to standing. Similar to scooting, you can best coordinate your power in your movement by saying in your head or out loud, “1,2,3 push.”

5. Once you are standing, feel your weight through your feet and take a deep breath. You are now prepared to move.

Q. “My family/doctors/friends think I need a cane or walker to help me walk...which should I get?”

A. If this question has been proposed to you or is in your mind, you should contact a physical therapist. Generally, swivel-wheeled rollators with brakes (e.g. a four-wheeled walking aid) work well, however this is case specific.

Once an assistive device is recommended, you must then be trained to use it in order to prevent the likelihood of losing your balance. Training is important with devices such as four-wheeled rollators as so as not to establish habits such as pushing the device ahead of your body, which will cause you to flex forward; standing with the device too close to your body, resulting in a higher likelihood of falling backwards; and/ or turning with feet outside of the wheels of the device.

With proper training, the device which is recommended to you will become an extension of your body, and it will move with you in order to enable you to be your best in your movement.

Before ordering a piece of equipment through your insurance, it is important to find out how much your insurance will cover and how often they will cover a piece of medical equipment for mobility (i.e. once every five years versus once a year with coverage renewal). With disease progression scooters, two will often be recommended. It is important to utilize your insurance coverage renewal). With disease progression scooters, two will often be recommended. It is important to utilize your insurance.

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Support for patients and families differentiates CurePSP CurePSP is strengthening its commitment to patients, families and care partners to help ease the burden of these terrible afflictions. We are the first "port in the storm" for families struck by the frightening diagnosis of PSP or CED. We will gradually be expanding our services to include the other prime of life diseases as resources allow. Our Family Conferences are known throughout the clinical field as the initial place to turn for education, guidance and fellowship among families struck by neurodegenerative diseases. The first annual Canadian Family Conference, held last spring in Ottawa, drew well over 100 people and marked the kickoff of our new Canadian affiliate. Our Care Partner Retreat this fall will provide information, networking and a day-long respite for people whose lives are often given over to caring for family members or other patients.

We will be strengthening our educational offerings to physicians and the healthcare field with new informational printed materials and video.

Awareness builds relevance CurePSP is engaging in a major effort to make these "hidden" diseases known to the public. To the average person, PSP will mean the gaming console and FTD will bring to mind the flower delivery service. However, putting these diseases on the "prime of life" platform immediately reminds people that neurodegeneration isn’t confined to the elderly, making it a more urgent concern.

We are working with a leading international public relations firm to "get the word out" through media exposure, including news releases and press interviews. We have published a new "case for support" brochure aimed at donors that will be supported by a portfolio of research offerings and patient profiles (please request a copy from our office). CurePSP will be holding events to bring together scientists with these donor prospects. We are creating powerful video content around patient stories in each of our six diseases. A link to our first profile of a PSP patient can be found on the homepage of www.curepsp.org. Over the next nine months, we will be working on redesigning our website to be more usable and visually compelling.

Multifaceted fundraising efforts The basis of our fundraising efforts is our Annual Fund, which relies on the generosity of thousands of donors, most of whom have been directly affected by prime of life diseases. We will continue to reach out to you and to build this base of support. Additionally, we are creating new materials to support outreach to major individual donors and foundations, most of whom have not been directly impacted by prime of life diseases but who see support of CurePSP as a productive investment. CurePSP will be holding small events in major markets to bring together these donors with our investigators, board and staff. The grassroots efforts of volunteers have long been critical to our sustainability. With new professional staff and systems, we will be able to provide additional support to volunteers and encourage local groups to think "out of the box" on possible fundraising events that combine enjoyment, fellowship and a serious purpose.

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One morning while Tyra Pritt, office manager at Heavy Duty Truck Repair, was driving to work she started thinking about the inevitable and unfair nature of CBD. She knew George had positively influenced many people throughout his lifetime, and family was waiting for George and Dianne at the airport.

"I had no idea what to do or how to deal with thousands of dollars, but it has always been important to us to deal honestly and with integrity with people's hard earned dollars ... I contacted CurePSP and asked for help, Kathleen Matarazzo Speca (CurePSP Vice President, Development and Donor Relations) was so helpful in offering help and suggestions, so it was then that I put her in touch with Tyra, and they took it from there.

Raising money was the easy part, keeping it a secret from George was the most difficult part. Updating over 500 people about the event without having him find out seemed impossible. But the employees at Heavy Duty Truck Repair worked diligently to keep George out of the loop the whole time. "There were a few near misses," said Dianne. "But I, or someone else, was able to redirect or come up with a plausible answer that satisfied George. Creative facial expressions and hand signals worked great to let people know when to stop talking.

Soon the Plaza Event Center in Longmont, Colorado, was booked and a "cover" had been put in place so it would stay a surprise. On August 2, 2014, George thought he was just going for a helicopter ride, courtesy of a kind customer. But after the helicopter landed, a limousine full of grandchildren and family was waiting for George and Dianne at the airport. "He knew when he got in the limo that something was up, but [he] was hoping it was a little family get-together," said Dianne. "However, when you are in a limo and have a photographer in the limo with you, that isn't everyday normal."

After the limousine driver made a few wrong turns accidentally, building more and more anticipation, they arrived at the Plaza Event Center. Once George saw all the cars in the parking lot (he knew it wasn't a little party. As they walked into the conference room, something amazing happened. "Everyone stood up and clapped," said Allen. "He was dumbstruck."

As [the party] started to take shape and I heard how many people were being invited and the response, I knew that we could be talking about a lot of dollars being raised," said Dianne. "He has done so much good in his life without asking to be recognized for it. And him being able to see he's done good in life was a great gift to him."

As the party commenced, guests enjoyed a catered BBQ meal, and picked up goody bags, bracelets and T-shirts—all while a professional photographer captured special moments. Then, both Tyra and Allen gave moving speeches about how thankful they were to work with such a kind, caring and selfless man. "In a time when the world seems like it is full of so many sad and ugly things, I have the gift of coming to work every day and being reminded that there are still a lot of good people in this world and a few extraordinary ones," said Tyra. "So thank you George for being such an inspiration to me and everyone here."

In the middle of the party, guests stood up and shared stories of how George had helped them. Allen said this was the best part of the event. He recalled many stories being told where people couldn't pay George for the work he did on their truck because they didn't have the money. So George would say, "You better get this thing outta here and get to work so you can pay me, then!"

"Giving George the gift of being able to see how many people he has truly touched in his life and hear the stories from people was amazing," said Tyra. "He has done so much good in his life without asking to be recognized for it. And him being able to see he's done good in life was a great gift to him."

George and family enjoying a limousine ride to the party.

"Eight years ago, George gave me an opportunity to work at Heavy Duty Truck Repair and helped me with some of my education because I hadn't finished it all yet," said Tyra.

"He was very understanding and willing to help me. He's always supported me putting my family first. He's like that with everyone." It was then that she decided the employees should throw George a surprise "appreciation party" so he could see how many people loved and cared for him. When she got to the office, she shared her idea with her co-worker, Allen Brossman.

"We're on it right now!" said Allen, the General Manager, when Tyra told him about her idea. "We started planning that very day and thinking of places we could hold it. I kept saying 'I don't think that place is big enough, or that one.'" They immediately talked to George's wife, Dianne Wood, about the surprise and asked her what she thought. While Dianne wasn’t sure she could handle planning such a large party on top of everything else that was going on, she had complete confidence in Tyra and Allen and gave them her blessing to proceed with their plan.

"They spent hours and hours with George at the shop, so they had the opportunity to see 'amazing' things happen on almost a daily basis," said Dianne. "And it seemed important to them to give back, so giving them the reins and letting them go seemed appropriate."

Tyra and Allen decided to invite close friends, family and loyal customers. They sent a letter out to over 500 customers explaining what was going on with George, asking for donations to throw the appreciation party and inviting them to come help the cumulative effect our lives have on others when we often don't even know who, or how we impact them," said Dianne. "To see people from all different walks of George's life—high-school, church, boy scouts, work, business associates, truckers, friends, neighbors, community, family—come together to tell us they cared and would be there for us, was beyond words."

Because of the generosity of everyone who attended the party and donated, once the payment was made for the party, there was money left over to buy George a star lift for George's office so he could safely be at the shop. And, an amazing $35,000 ($25,000 was the initial donation to CurePSP, with an additional $10,000 collected and donated later) was donated to CurePSP. If you’re interested in having an event that benefits CurePSP, please contact Kathleen Matarazzo Speca at special@curepssp.org or 800-457-4777 ext. 5672. An experience like George’s is life changing, and, like Allen said, “Everyone deserves an appreciation party.”
Everyone Deserves an Appreciation Party

George Wood, an independent, modest, generous and hard-working man, built Heavy Duty Truck Repair in Longmont, Colorado, from the ground up, inspiring his employees with his positive spirit and outlook on life. So when he was officially diagnosed with corticobasal degeneration (CBD) in January 2014, his family, friends and employees were devastated and decided to do something special for him.

One morning while Tyra Pitt, office manager at Heavy Duty Truck Repair, was driving to work she started thinking about the inevitable and unfair nature of CBD. She knew George had positively influenced many people throughout his lifetime, including her, and decided that showing him how much he meant to others would be a great gift.

“Eight years ago, George gave me an opportunity to work at Heavy Duty Truck Repair and helped me with some of my education because I hadn’t finished it all yet,” said Tyra. “We’re on it right now!” said Allen, the General Manager, when Tyra told him about her idea. “We started planning that very day and thinking of places we could hold it. I kept saying ‘I don’t think that place is big enough, or that one.’” They immediately talked to George’s wife, Dianne Wood, about the surprise and asked her what she thought. While Dianne wasn’t sure she could handle planning such a large party on top of everything else that was going on, she had complete confidence in Tyra and Allen and gave them their blessing to proceed with their plan.

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Dianne and George Wood and their family. “He was very understanding and willing to help me. He’s always supported me putting my family first. He’s like that with everyone.” It was then that she decided the employees should throw George a surprise “appreciation party” so he could see how many people loved and cared for him. When she got to the office, she shared her idea with her co-worker, Allen Brossman.

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Tyra and Allen decided to invite close friends, family and loyal customers. They sent a letter out to over 500 customers explaining what was going on with George, asking for donations to throw the appreciation party and inviting them to attend. They hoped to pay for the event with the donations and then give any leftover money to CurePSP, but they didn’t anticipate how many people would respond to their request.

George Wood and his wife, Dianne. “As [the party] started to take shape and I heard how many people were being invited and the response, I knew that we could be talking about a lot of dollars being raised,” said Dianne. “I had no idea what to do or how to deal with thousands of dollars, but it has always been important to us to deal honestly and with integrity with people’s hard earned dollars.”

“Raising money was the easy part, keeping it a secret from George was the most difficult part. Updating over 500 people about the event without having him find out seemed impossible. But the employees at Heavy Duty Truck Repair worked diligently to keep George out of the loop the whole time. ‘There were a few near misses,’ said Dianne. ‘But I, or someone else, was able to redirect or come up with a plausible answer that satisfied George. Creative facial expressions and hand signals worked great to let people know when to stop talking.’”

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Soon the Plaza Event Center in Longmont, Colorado, was booked and a “cover” had been put in place so it would stay a surprise. On August 2, 2014, George thought he was just going for a helicopter ride, courtesy of a kind customer. But after the helicopter landed, a limousine full of grandchildren and family was waiting for George and Dianne at the airport. “He knew when he got in the limo that something was up, but [he] was hoping it was a little family get-together,” said Dianne. “However, when you are in a limo and have a photographer in the limo with you, that isn’t everyday normal.”

“All the people meeting us were being invited and the response, I knew that we could be talking about a lot of dollars being raised,” said Dianne. “I had no idea what to do or how to deal with thousands of dollars, but it has always been important to us to deal honestly and with integrity with people’s hard earned dollars.”

“After the limousine driver made a few wrong turns, accidentally building more and more anticipation, they arrived at the Plaza Event Center. Once George saw all the cars in the parking lot, he knew it wasn’t a little party. As they walked into the conference room, something amazing happened. ‘Everyone stood up and clapped,’” said Allen. “He was dumbstruck.”
Disease in a Dish:

VISITING DR. TEMPLE’S LAB AT THE NEURAL STEM CELL INSTITUTE, RENSSELAER, NY

ALEX KLEIN, PhD
CUREPSP VICE PRESIDENT-SCIENTIFIC AFFAIRS

When Dr. Sally Temple speaks about stem cells, one can see the passion with which she carries out research at the Neural Stem Cell Institute (NSCI) in Rensselaer, NY: “By growing human brain cells in a dish from patient [skin] cells, we can investigate brain diseases with the aim of finding effective treatments.” Dr. Temple is the co-Founder, Principal Investigator, and Scientific Director of the NSCI, and one of the world’s leading scientists in stem cell research. Her research is dedicated to developing regenerative stem cell therapies for diseases of the nervous system, one of which is progressive supranuclear palsy (PSP).

As part of CurePSP’s new strategy to identify promising research groups who may accelerate the arrival of novel therapeutic approaches in PSP and other prime of life diseases, I travelled to upstate New York to visit Dr. Temple’s lab. Her research has become of particular interest as she and her team use so-called induced pluripotent stem cells (iPSCs) to create brain cells and simulate disease conditions in a (petri) dish. iPSCs are harvested from a small skin sample (skin biopsy) from adults. The cell donors can be healthy controls as well as PSP patients.

The great advantage of this method is that the cells from the patients carry the gene mutations causing the devastating symptoms of PSP. Dr. Temple then uses specific growth factors to drive these skin cells back into a state where they can produce any cell type of the body (becoming a stem cell, again). Finally, Dr. Temple’s team adds another cocktail of chemical components to the cells turning them into brain cells.

These electrically active brain cells, called neurons, look almost as if they were taken directly from the brain of the respective donor with the genetic mutations. This in turn means that the cells in the dish undergo similar disease-processes (pathological changes) as they would in the PSP patient’s brain. Hence, Dr. Temple talks about creating a “disease in a dish” model. And now that the cells are ready to be investigated, the following questions are discussed at the NSCI: What is going wrong inside the cells? Why are the cells dying? Can we prevent that and can we test new drugs on those cells?

Before testing new drugs, however, the actions of the disease need to be understood. This is when Dr. Temple’s research becomes a vital part of CurePSP’s mission to find a cure and new treatments for PSP and related diseases. Molecular and genetic changes can be investigated in these iPSCs living in a dish, and fascinatingly, new therapeutic approaches can be tested on human cells carrying the “real” genetic mutations from PSP patients.

One of the key features of PSP is the misfolding of proteins within the affected neurons. It has been generally accepted that the misfolding (misassembling) of a protein called Tau is one of the key disease processes in PSP. Not only is Tau misfolded, but it also forms large toxic clumps in the cells, which make the cells fail and eventually die. To make things worse, normal Tau is actually a very useful protein that is important for the metabolism and the structure of a cell. If a cell loses “healthy” normal Tau, the cell cannot function properly anymore.

These aspects of the disease can be modeled in the Temple lab by adding abnormal (mutated) Tau protein to the cultured cells and by studying how it causes impairment and eventual cell death. Using advanced time-lapsed microscopy, the impact of abnormal Tau can be observed at different stages and the pathological changes can be visualized. Now that Tau can be traced and imaged, the Temple lab is working on new therapeutic genetic approaches to clear abnormal Tau from the affected human cells. The method behind this will most likely be something like a flu shot: antibodies should find the abnormal Tau, bind to it, and break it down to a state when it is not harmful anymore. Once a safe method of reducing Tau has been shown in the stem cell models, the goal is to move it rapidly through the pipeline towards a clinical trial.

I spent a full day in Dr. Temple’s lab and had many opportunities to speak about science to all group members, including senior scientists, students and summer interns. I could see the hard work, the passion and the enthusiasm of the team for finding a cure for PSP and related diseases. It was a great and inspiring experience to be part of a team that is truly moving the pipeline towards a clinical trial, and the actions of the disease need to be understood. This is when Dr. Temple’s research becomes a vital part of CurePSP’s mission to find a cure and new treatments for PSP and related diseases. Molecular and genetic changes can be investigated in these iPSCs living in a dish, and fascinatingly, new therapeutic approaches can be tested on human cells carrying the “real” genetic mutations from PSP patients.

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The first CurePSP Canadian Family Conference took place in Ottawa, Ontario, Canada, June 12-13, 2015, and exceeded all our expectations! The conference began on Friday evening with a support group meeting for all attendees. We anticipated that about 20 people would participate, but were pleasantly surprised to welcome many more.

It was an emotional evening for everyone as we listened to those who were recently diagnosed with PSP, CBD or MSA, had lost loved ones to one of these diseases, or were there to support friends and families on their long and winding journey. It was incredible to hear the touching and heart-wrenching stories and realize that we had people attending our first conference from places like Texas, Florida, New Mexico, New York, Ontario and Quebec, just to name a few. We became a family of sorts that night, and came away with a strong connection and lifelong memories.

Saturday was a full day. We heard from movement disorder experts, which included neurologists and a physiotherapist. Attendees learned about coping mechanisms for both physical and psychological issues and methods of expanding support to caregivers and patients. And once again, many shared personal stories – some humorous, some angry and some that brought tears to the eyes of most of us in the room.

We would like to extend our heartfelt appreciation to Dr. Grimes and Dr. Porter, who provided invaluable insight into PSP, CBD and MSA, including disease origins, mechanisms and potential treatments. Many thanks also go to Joellyn Fox, who provided us with practical (and humorous) tips for dealing with some of the common movement issues that patients and their caregivers face, and Tish Caruana, who emphasized that we must “care for the caregivers” as much as we do those who are suffering through the diseases.

All of us who attended the Canadian Family Conference were thrilled and relieved to realize that we are not alone in our battle. It is obvious that there is indeed strength in numbers, and we hope to bring an even larger number of you to our conference next year. Plan now to join us in Hamilton, Ontario for our second Canadian Family Conference, May 13-14, 2016.

CurePSP Canada president, MJ Overby (standing), with attendees.

For more information about the Canadian Family Conference or CurePSP Canada, please contact:

MJ Overby
President, CurePSP Canada
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1-844-CUREPSP
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Disease in a Dish:

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ALEX KLEIN, PHD
CUREPSP VICE PRESIDENT-SCIENTIFIC AFFAIRS

2015 Canadian Family Conference

DEBBI GRIoux
CUREPSP CANADA STAFF

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Upcoming Events

OPPORTUNITIES FOR LEARNING AND SUPPORT

SPECIAL EVENTS
Patrick Dixon - Continental Divide Trail Hike
Begins Wednesday, April 15, 2015 through Fall 2015

Robert Wolfe - Coast-to-Coast Charity Bicycle Ride
Begins Sunday, July 26, 2015

Urbanathalon Sprint - Randy and Kevin Subramany
October 24, 2015
Corona, New York

12th Annual CurePSP Awareness and Memorial Walk
Saturday, March 12, 2016
Marco Island, Florida

CONFERENCES
CurePSP 2015 International Research Symposium
Thursday, November 5 - Saturday, November 7, 2015
La Jolla, California

2016 Western Family Conference
Saturday, February 20, 2016
San Francisco, California

NEW SUPPORT GROUPS

Hawaii - Honolulu
Information: For anyone dealing with PSP, CBD, MSA, or atypical Parkinson’s
Location: Waikiki Banyan, 201 Ohua Avenue, Honolulu, HI 96815
Meeting Time(s): 2nd Saturday of each month from 10:00 am - 11:30 am
Facilitator: Ozzie Boyle, 206-793-8648, ozzieboyle@gmail.com

Virginia - Fairfax
Information: Patients and care partners affected by Parkinson’s, PSP, CBD, MSA and other atypical Parkinsonian disorders
Location: The Virginian, B1 Assembly Room, 9229 Arlington Blvd., Fairfax, VA 22031
Meeting Time(s): Every Wednesday at 5:00 pm; care partners group led by care partners and patient group led by speech language pathologist.
Facilitator: Matt McKeon, 703 385-0555, ext. 5392, mattrmckeonslp@aim.com