



Our family learned many important things from this experience that we want to share, in hope that it will help others:

1. Get second (or third) opinions early, especially for unexplained symptoms.
2. Push to get to a top neurologist and don't accept an unconfirmed or non-specific diagnosis. We did for over a year and I regret it now.

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Throughout all of this, she continued attending church at Saint Mary Immaculate Parish in Lakeport, California, showing her strength and commitment to her God.

She wanted to (and we continued to) try to keep life as normal as possible, going to concerts, having family get together, getting out on the lake, traveling to see family and friends as well as the visits to doctors. This included a big family trip to Los Angeles in October 2010 to see our youngest daughter perform in "Singin' in the Rain" and another to Oregon to see the OHSU doctors in December 2010.

In early January 2011, the muscles that allowed her to swallow quit working but, per her documented wish, she did not want to be maintained with a feeding tube or respiratory equipment. As a longtime fan of the Green Bay Packers, she listened to them win the NFC Championship and secure a place in the Super Bowl, and then left us 10 minutes afterward. On January 23, 2011 at home with her family around, she passed over to be with her God.

We did opt for brain donation to the Mayo Clinic in Jacksonville, Florida. We had kept copies of all the medical records from the various doctors we saw and provided them to Mayo. A month later, we received the confirmation that it was PSP with Argpyrophilic Grain Disease (AGD). According to the Mayo Clinic, AGD co-occurs with PSP in about 30% of PSP cases.

Support from our family, our church, the Bay Area PSP/CBD/MSA Support Group, the Lake County Hospice organization, friends, neighbors, OHSU, her physical therapist, her health aides, and the CurePSP organization all helped us make it through the rough patches. Thank you! We couldn't imagine going through this without this constant love and support. Their warmth kept Jackie's determination going, as well as our family's. We extend our deepest gratitude.

Memorial contributions may be made to CurePSP, in order to fund research for a cure for progressive supranuclear palsy (PSP), as well as physician education and caregiver support, by visiting give.curepsp.org and identifying the donation "in memory of The Jackie Myers Family Fund."



Continued from Page 4

3. Make decisions early, while it can be a fully conscious and in-depth discussion on feeding tubes (Jackie did not want one), Do-Not-Resuscitate orders (she wanted DNR), hospitalization or die-at-home (she wanted to die at home), and discuss these with the whole family and the doctors, so everybody knows the plan. Also, reduce the plan to writing.

4. Continue exercise as long as possible, as it extends life.

5. Work with doctors, hospice, and others to try to make life as normal as possible. This should include travel and visiting others as much as possible. Keeping the mind active delays the disease's progression.

6. Check out available clinical trials. Jackie participated in one and I know it helped her. One of them will eventually work and it would be better to be a participant than learn about it afterward. I believe science will be able to stop the advancement of the disease shortly.

7. As the caregiver or patient, be proactive, participate in support groups, go to presentations on the disease, and perform online research. The disease you know is better than the one you don't know. Yes, the future can be bad and disappointing, but knowing what to expect does make it easier.

8. Keep a "binder" or file with notes on each medical visit and copies of all test results from the various doctors / hospitals. You (the caregiver) are responsible for making sure that each doctor knows what the others are doing and coordinating all of the care. This is invaluable.

can reach out to your address book and we have just the tools for it! Another way to raise money that can be fun for the children is to organize a pumpkin decorating contest for Halloween. Charge a small entry fee, get a local farm to donate the pumpkins and ask each parent to bring a few decorating supplies. (No carving involved – just markers, construction paper, yarn, glue, etc.) Provide punch and cookies as refreshments and give a prize for the first, second and third place best pumpkins.

November – As the air becomes brisk once again, generate contributions by having a movie night fundraiser. Many movie theaters will be able to offer you their space for a discounted rate or for free for a special group movie marathon. Choose a movie theme with the theater and advertise it around town and in the local newspapers. Ask friends to volunteer to sell tickets. Whether it's a family oriented matinee or a grownup's date night, this event is sure to be a success.

December – Like the month of October, this is a great time to plan a writing campaign. You can include a giving envelope in your holiday cards, which CurePSP can provide for you. You can send out a special announcement through a letter or a personalized online donation page and ask for gifts in honor or in memory of your loved one. This month is one of the most crucial months for CurePSP to raise funds. As always, your support is greatly appreciated.

Don't forget, CurePSP also offers an option to create a "named fund" after your loved one. To learn more about this option, please e-mail me at spec@carepsp.org or call 1-800-457-4777, extension 5672.

I look forward to hearing from you. Thank you for your support.



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MISSION

Increase awareness of progressive supranuclear palsy, corticobasal degeneration, and other atypical Parkinsonian disorders; fund research toward treatment, cure and prevention; educate healthcare professionals; and provide support, information and hope for affected persons and their families.

LEGISLATIVE PROGRESS FOR RARE DISEASES

*Bruce Janele
Director, Communications & Marketing*

There is new hope for the millions of Americans that have rare diseases. *The FDA Safety and Innovation Act (S. 3187)*, a bill of major importance to the rare disease community, was approved by the US Senate on June 27, 2012. The bill had previously passed the House of Representatives with bipartisan support, and now moves to the President's desk to be signed into law. Important highlights include:

- Better consultation with rare disease experts
- Increased access to new medical treatments
- Increased development of medical devices for those with rare diseases
- Potential for acceleration of promising new therapies

With PSP, CBD, and other atypical Parkinsonian disorders among the small group of rare diseases that exist, this bill paves the way for those with the diseases to receive better medical treatment in the near future.

UPCOMING EVENTS OPPORTUNITIES FOR LEARNING AND SUPPORT

WEBINARS

How to Help a Grieving Friend
Fred Schneider
Professional Healthcare Resources
Tuesday, July 24, 2012, 4:00pm - 5:00pm EDT

FAMILY CONFERENCES

PD and Parkinsonism Caregiver Symposium
Saturday, August 14, 2012
Crowne Plaza Foster City
Foster City, California

Living with PSP

Saturday, August 25, 2012
10:00am - 2:30pm
Christ Presbyterian Church
Edina, Minnesota

SPECIAL EVENTS

CurePSP Memorial Scramble Golf Outing
Sunday, July 8, 2012
Port Huron, Michigan

Amica Triathlon
Sunday, July 15, 2012
Ocean Beach
New London, Connecticut

Nantucket Triathlon
Saturday, July 21, 2012
Jettes Beach
Nantucket, Massachusetts

7th Annual Ken Jennings Putt for PSP
Saturday, July 28, 2012
South Shore Golf Club
Syracuse, Indiana

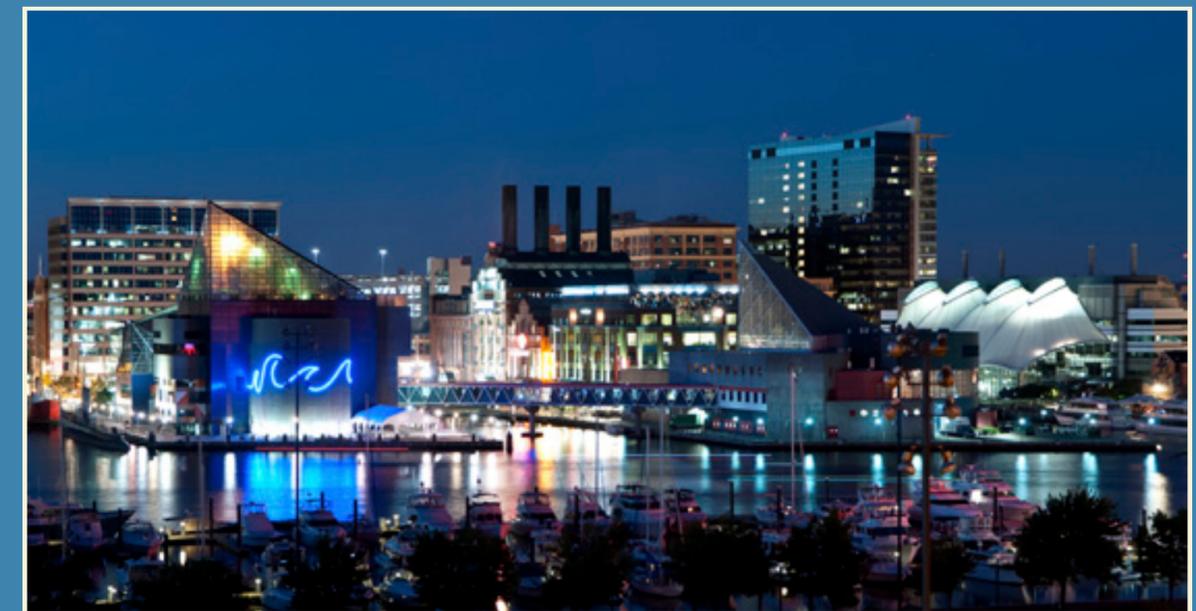
Cure the Pain
Sunday, July 29, 2012
Gaithersburg, Maryland

Busdeker Ironman Triathlon
Sunday, September 9, 2012
Lake Monona
Madison, Wisconsin

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BECAUSE HOPE MATTERS

Making a Difference in the Lives of People with PSP, CBD and Other Atypical Parkinsonian Disorders



BALTIMORE CAREGIVER CONFERENCE A SUCCESS

*Trish Caruana, MSW
VP of Programs & Education*

"We need information about this disease. We need to know where to find resources. We need to understand what treatments are available and who the best physicians are to care for our loved ones. We need someone to advocate for us. We need support to get through this disease. We need help."

In speaking with family members from all over the U.S. and other countries, the themes that emerge are universal. Whether someone lives in New York City, Great Falls, Montana, Toronto, Canada or New Delhi, India, patients and their families battling diseases like PSP/CBD and other atypical Parkinsonian disorders feel alone. They feel alone because so many healthcare providers are not familiar with the disease, they feel alone because resources are limited, and they feel alone because they don't know anyone else who is coping with the disease. The question becomes, beyond support groups, what can CurePSP do to help bring people together?

For the past several months, we have been working with the staff at the Johns Hopkins

Parkinson's Center of Excellence to develop a half-day conference for caregivers. We decided that a conference designed for caregivers only would provide a unique environment where people could share their thoughts and feelings openly, at the same time doing something for themselves.

The conference was held on June 16, 2012 and was very well received with 25 caregivers in attendance. There were four presentations by local healthcare experts:

- *Your PSP Management Plan - Creating & Working Together with Your Treatment Team*
Becky Dunlop, RN, BSN
The Johns Hopkins Parkinson's Disease and Movement Disorders Center

- *Quality Time - Understanding Palliative Care & Hospice*
Casey Young, LPN
Professional Healthcare Resources

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ADAPTING TO SPEECH PROBLEMS IN PSP/CBD

Laura Purcell Verdun, MA, CCC/SLP
Otolaryngology Associates, PC

Progressive supranuclear palsy (PSP) is a rapidly progressive disease dominated by motor symptoms. Changes in speech is an unfortunate but classic hallmark of PSP. These changes often occur early in the disease onset, which can help to distinguish it from Parkinson's disease and other Parkinsonian syndromes. The intent of this article is to serve as a guide, providing information and strategies to enhance speech specific to PSP. Management of speech problems requires changing intervention strategies as the disease progresses. Consultation with your physician and speech pathologist are recommended to tailor the program to your specific needs.

What problems can I expect with talking?

Problems with communication tend to be progressive and fairly consistent across all individuals with PSP. Dysarthria is a general term used for the speech disorders that result when the muscles cannot move with the correct range of movement, speed, force or coordination. Dysphonia is a general term used for the voice disorders that affect the sound source. To address the changes in communication, some comparisons with Parkinson's disease (PD) may provide some additional insight.

Speech characteristics can distinguish PSP from PD. Change in speech is more prominent in PSP, whereas change in voice is more prominent in PD, this being an important distinction which may enhance the differential diagnosis early on. If not an initial symptom, change in speech is an early symptom of PSP, which is generally not the case in PD. In PSP, the dysarthria is often mixed, a hypokinetic dysarthria accompanied by some other type of dysarthria, usually spastic or ataxic; whereas in PD, hypokinetic dysarthria predominates. The speech and voice of PSP is characterized by strained voice, slowed rate of speech, emotional lability and palilalia. Palilalia is the compulsive repetition of utterances, often in the context of increasing rate and decreasing loudness. The speech and voice of PD is characterized by weak voice, rapid rate of speech, imprecise articulation and occasional difficulty initiating speech, and tremor. Change in voice is more characteristic of PD and develops later in the PD disease course. Dysarthria in PSP can be severe even in the early stages, and anarthria, or the inability to speak, does ultimately result in later stages of the disease.

If you would like to help us create a similar caregiver conference in your area, please contact me at 800-457-4777, ext. 5667, or caruana@curepsp.org.

What are some tips to enhance communication?

Most people with communication difficulties prefer to attempt verbal communication for as long as possible, even when their speech becomes hard to understand. The following strategies are designed for the listener and to enhance the communication environment:

- Eliminate distractions, and reduce background noise (TV, radio, newspaper, large groups of people, close the door, etc.)
- The listener should face the speaker and be an active listener
- Keep questions and comments brief
- Ask one question at a time, allowing time for a response
- Stick with one topic at a time
- Ask for the topic of the message so you can use context cues to help with interpretation
- Ask targeted "yes/no" format questions
- Pay attention to gestures and facial expressions
- Ask for clarification when you do not understand, or repeat what you think was said in the form of a question, such as, "Did you say...?"
- Try to keep to familiar topics
- Allow enough time for the person to convey his/her message
- Give the person choices to ease decision making, such as, "Do you want coffee or tea?" rather than, "What do you want to drink?"
- Be patient

What are some specific strategies for the speaker?

Consult with a speech pathologist who will recommend specific exercises to address limitations in speech and voice. Here are some strategies which may enhance the speaker's success:

- Keep sentences short
- Repeat the entire sentence when necessary, versus an isolated word, providing a context for the listener
- Exaggerate and be deliberate with all speech sounds
- Take a deep breath before speaking, and breathe often
- Use gestures
- Speak one sentence at a time without immediate repetition, remembering potential for palilalia
- Speak loudly and slowly

Does voice and speech therapy for PD help with PSP?

Strategies appropriate and beneficial to PD have limited impact in PSP. Reports of successful speech intervention for individuals with PSP are rare. Reasons include the cognitive problems that place considerable burden on the spouse, the relatively rapid progression of the disease and delay in an accurate diagnosis, perhaps delaying referral to therapy services.

A speech pathologist can be helpful at all stages of the disease, preferably with early involvement and intervention emphasizing good speaking habits, prior to the underlying problems becoming so severe that new learning is difficult. It is critical to discuss with the therapist the limitations and severity of the communication problem, as well as the communication needs. Therapy efforts should focus on increasing loudness, articulatory precision, minimizing repetitions in the setting of palilalia and enhancing awareness and participation in communication efforts.

A therapy program called the Lee Silverman Voice Treatment (LSVT) is frequently applied to the communication changes in PD. The emphasis of this program is "Think Loud," in an attempt to enhance voicing effort and maximize performance. This is appropriate to the PD communication impairment, because the primary problems experienced are low volume, rapid rate of speech and imprecise articulation. It may not have the same impact in PSP, given that the speech problem is more pervasive; however, it is reasonable to pursue this strategy for a trial period of time.

What is assistive or alternative communication?

When speech is no longer meeting important communication needs, or when speaking is takes effort and is tiring, communication is more efficient using alternative means. Handwriting is the most natural, accessible and portable means of alternative communication. Alphabet boards can be used to identify the first letter of each word as it is spoken or to spell the entire message. Communication can be supplemented with a portable typing system. Messages can be typed in a letter-by-letter fashion. When these do not work, an augmentative communication system might provide a reliable, consistent and easy-to-use method of communication.

How can I find someone to recommend a communication device?

The speech pathologist is responsible for evaluating the patient and teaching

the patient to use the system for communication. Ask the clinician if he/she has experience in working with assistive devices and augmentative communication systems. An evaluation determines which device best meets the needs and abilities of the person with PSP. Evaluations usually are conducted by a team of professionals, including a speech pathologist, and perhaps an occupational therapist, a physical therapist and a rehabilitation engineer. The evaluation will include an assessment of speech, language, visual and physical motor abilities. An evaluation by objective professionals will allow one to make an informed choice from firsthand experience with a variety of devices. The type selected for someone with PSP will largely depend on his/her cognitive, physical and visual abilities, and the needs for communication. These teams usually work in centers specializing in assistive technology or augmentative communication, located mainly in hospitals, university clinics and not-for-profit organizations. These centers typically have a variety of equipment available to them so that the person can try a number of devices that might meet their needs. Some even allow for a loaner period to further confirm the appropriateness. Insurance and private organizations often cover the cost of such devices with appropriate supportive documentation.

Referrals to professionals who specialize in augmentative communication can be obtained from the following organizations:

- ASHA - American Speech-Language-Hearing Association, 800-638-8255
- ISAAC - International Society for Augmentative & Alternative Communication, 416-385-0351
- USSAAC - United States Society of Alternative & Augmentative Communication, 941-925-8875

What is a voice amplifier, and will that help me?

When the muscles involved with voice production and breathing are affected, resulting in a weak voice, a voice amplifier can increase the loudness of speech. This may minimize the strain and fatigue associated with speaking. An amplifier tends to be most beneficial when the voice impairment surpasses the speech impairment. When selecting an amplifier, consider the quality of the amplifier, cost effectiveness, portability and a location to secure the microphone. Headset microphones are ideal for positioning and ease of use. There are many devices available, but those are just a couple of suggestions.



DEVELOPMENT UPDATE

Kathleen Matarazzo Specca
VP of Development & Donor Relations

Special thanks to all of our volunteers who coordinated fundraising events and writing campaigns to support the vital programs and services of CurePSP. We couldn't have done it without you!

I'd like to take this opportunity to introduce you to Lauren Smith, our new Development Services Manager. Lauren is working with volunteers on a variety of fundraising endeavors. Please contact Lauren (smith@curepsp.org or 1-800-457-4777, ext. 5674) or me to learn more about how you can become a special event volunteer too!

In this issue and future newsletters, we'll be sharing a variety of fundraising ideas to help you plan an event beginning with July through December. Visit our website for a complete list of month-to-month fundraising suggestions from January through December. Each month gives a suggestion of how you can raise awareness and funds for CurePSP, but the list is certainly not limited to these events.

Wine tastings, walk-a-thons, dances, dinners, golf tournaments, and other events can be scheduled any time during the year. Plus, if you or a family member like to run, there are community marathons and triathlons that you and your family members can participate in while raising money for CurePSP. We even have special software applications that allow you to have your very own webpage, an area to upload the email addresses of your friends and family so that you can send out messages, reminders, thank you notes, etc., as well as special fundraising options to help you with these and any events you choose to participate in or organize. In addition, we welcome your ideas for other special events.

Check out the following link to see a recent walk-a-thon that raised over \$6,000 using our Friends Asking Friends software:

<http://www.kintera.org/faf/home/default.asp?ievent=1020548>

Here are some month-to-month

fundraising ideas that you can also find on our website:

July – Entice all of your friends and family over for a summer cookout – a wonderful way to socialize, relax and enjoy good food for a great cause. Ask attendees to bring one dish and a donation. CurePSP can provide you with a donation request letter for you to bring to local stores for potential item donations. If you would like to add a twist to your cookout, incorporate a grill-off competition into the afternoon! Ask contestants for an additional donation amount and select a panel of judges. Have a prize ready, such as a gift basket of cookout items or a decorated spatula. Good luck grillers!

August – During the blistering month of August, recruit your friends and family to cool off with a car wash fundraiser! Find a place willing to offer you their space – they must have a water source available for a hose. Schools, gas stations, fire departments, restaurants would all be good locations. Bring signs, buckets, sponges, towels, soap and a garden hose. Advertise your event, along with a secured rain-date, just in case! Make flyers and contact your local newspaper, as well. Be sure to show up with some sunscreen and small bills for change and enjoy the day.

September – During the Fall months, there are always various community events occurring, such as 5K runs, walks, bike-a-thons, etc. CurePSP can assist you in finding one to register for or help you set up your very own event. Don't forget, CurePSP has special software to set up your own fundraising webpage for this event, along with many other features, such as pictures, a goal thermometer, and easy access for donors to contribute to your online event.

October – Starting a writing campaign is a simple way to generate donations through one simple step – sending a letter. CurePSP will provide you with return envelopes for donations and templates for your letters, or we can set up a special donation page with a link you can send to family and friends. You can also entice potential donors by selling CurePSP wristbands. There are various ways you

MY WIFE, JACKIE

Phillip Myers

She was born Jacqueline Raelene Araujo in Honolulu, Hawaii, in 1938. A true "island girl" and an artist from a young age, Jackie enjoyed painting, with much of her work in oils and pastels, drawing inspiration from Hawaii's beautiful flowers, beaches and seascapes.

She attended the University of Hawaii and embarked on a career as a medical secretary/artist during which she sketched and colorized surgical procedures with intricate detail that could not be captured by the color photography of the time.

While working as an executive secretary in the early days of the computer industry, she met Phil, her "Midwestern sweetheart." We fell in love, married, and raised our young family on Oahu until a job relocation prompted us to move to California's Silicon Valley in 1974.

A loving wife and mother, Jackie devoted herself to her husband, her children, and her church, where she actively contributed her time, energy, and creative talents at Saint Anthony's Parish in Kailua, Hawaii; Saint Victor's Parish in San Jose, California; and Saint Thomas More Catholic Community in Paradise, California.

Jackie continually nurtured her creative spirit as an avid crafter and Cub Scout den mother, as well as in her love of baking and her passion for travel. Together we visited many historic and religious sites around the world.

Once the children were of school age, Jackie returned to the workforce and enjoyed 12 years as office manager at Vinci Park School in San Jose. We retired in 2002, moving to Paradise, California, and subsequently, Lakeport, California.

Her involvement with progressive supranuclear palsy (PSP) began in late 2003 / early 2004. It started with fidgeting, frustration, balance problems, and falls, but we had no indication that it was serious. However, a major fall later in 2004 brought our attention to what we began to realize was a significant issue. During 2004 and 2005, we worked with our primary care physician and neurologist, but become increasingly frustrated with negative test results that piled up without a real diagnosis. Jackie's fine motor movements were affected, but despite this, she continued her artistic endeavors by making an Easter banner for church, among other things. Her eyesight deteriorated (fuzzy and some double vision) although we had not yet connected that to her disease. Double cataract surgery did not solve the problem and, in retrospect, was unnecessary as PSP was the true cause.

The local neurologist finally indicated an inability to diagnose her and referred us to



a major clinic (Mayo, Scottsdale). Several visits and many more tests throughout 2007 resulted in no firm diagnosis, while her symptoms continued to worsen. We pushed for another opinion from a nationally recognized expert. In the Fall of 2007, Dr. Jay Nutt, Director of the Movement Disorders Department of the Oregon Health and Science University (OHSU), finally gave us the firm diagnosis of PSP. While it was "bad" news, for the first time, we really knew what we were dealing with.

During the next few years, Jackie progressed from a cane to a walker (never worked well) to a wheelchair. Since exercise was important, we obtained a body weight support treadmill. Her physical therapist was able to get her on it multiple times a week, therefore keeping her heart and blood flow very active. We have been told by Dr. Nutt and others that this extended her life another year.

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- *The Future is Today - Caregiver Stress*
Dr. Paul Short
The Parkinson's Coach

- *Keeping Your Family Strong - Middle & Later Stages of the Disease*
Trish Caruana, MSW
CurePSP

The presentations led to discussions which were emotional at times, as people shared their frustrations, worries and sadness as they experience the disease with their loved one. There was time for networking in between sessions and many people stayed after the conference to talk with the presenters and each other, exchanging names and phone numbers. The evaluations we received indicated that people felt the topics and presenters addressed their needs and that they would have benefited from even more time to explore their emotions and to connect with one another.

This conference was a great opportunity for CurePSP to collaborate with the National Parkinson's Foundation and to design an event for small audiences that facilitated an open discussion and sense of community. The overriding sense that attendees had when leaving the conference was that they were *not* alone, that others did truly understand, and that hope can infuse each day with love and gratitude.

If you would like to help us create a similar caregiver conference in your area, please contact me at 800-457-4777, ext. 5667, or caruana@curepsp.org.



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