

FTD/PPA Caregiver Education Conference
March 11, 2011**Question and Answer Session**

Answered by Joseph Cooper, MD, Darby Morhardt, MSW, LCSW, Mary O'Hara, AM, LCSW, Jaimie Robinson, MSW, LCSW, Emily Rogalski, PhD, HyungSub Shim, MD, and Christina Wieneke

Medication**1. Are there any vitamins that you would recommend to give to patients to supplement a good diet?**

A standard multivitamin is a reasonable supplement, but there are no specific vitamins to recommend for PPA/FTD.

2. Are any effective medications/pharmacological breakthroughs on the horizon in the treatment of PPA?

Significant amounts of research are underway for PPA, but no new medications are close enough to be considered on the horizon.

3. I read recently about some drugs being used for PPA. These I believe were being researched at the University of Pennsylvania and Johns Hopkins. One of these drugs was already being used for malaria. What do you know about these?

At this time, there are no major drug trials currently enrolling for PPA. Unfortunately previous drug trials have not shown benefit in PPA.

4. Are there any prospects in stem cell research for PPA patients? There has been some recent news as to a breakthrough here at Northwestern.

While, there is very exciting research at Northwestern University looking at the potential that stem cells have to help people with neurological conditions, more intensive research is needed. There is currently no research looking at stem cell therapy specifically in PPA.

5. Can you tell us more about the medication you mentioned which shows improvements in mice with regard to tauopathies? Anything available experimentally for nonfluent aphasias?

There are many different substances that have been researched in animals and people to combat tauopathies. These substances have various ways of working, such as changing how abnormal tau proteins are created or cleared, or targeting other abnormal proteins involved in dementias caused by tauopathy. However, none of

these are currently being tested in PPA. This is partially because PPA is caused by a variety of different kinds of changes to the brain cells, only some of which are tauopathies.

- 6. Please address the issue of alcohol use and behavioral variant FTD. My spouse likes the occasional glass of wine/beer, but at times drinks too fast. He is insistent that he doesn't want to give this up. If I'm not overseeing, he will consume too much.**

Unfortunately, some people with FTD must be closely monitored or they will consume too much food or drink. Alcohol can be a particularly difficult problem in FTD because judgment is impaired by the illness and further impaired by the alcohol. You might try using distraction or redirection with something else that interests him around the time that he prefers to drink. For example, if he has wine with dinner, plan to go for a walk, or out for ice cream right after dinner so that his is not able to refill his glass. You might also consider telling him that the doctor has limited his drinking due to medication interactions. If it is not possible for the person to give up alcohol completely, consider offering a non-alcoholic wine/beer or add water to the beverage.

- 7. Is it OK to give a PPA patient a small amount of liquor on the weekend who doesn't have any dietary restrictions? The patient is 94 years old. He has no high blood pressure or cholesterol problem.**

If the patient has been able to tolerate a small amount of alcohol without adverse effects such as increased confusion, agitation, or aggression, it is probably reasonable to continue from the perspective of the PPA. Consult the patient's physician regarding the specific case.

- 8. Which antipsychotic medication can be useful for a patient with FTD exhibiting delusional thinking, impulsive behavior, and restlessness?**

There are multiple antipsychotic medications, which can be useful in addressing symptoms. Please note that all antipsychotic medications carry the black box warning, which describes an increased risk of death in elderly dementia patients. If possible, work with a Geriatric Psychiatrist who is informed on these medications for persons living with a dementia diagnosis.

- 9. Which drug has been shown to have the least side effects and without the "black box" warning?**

The category of "Antipsychotic medications" carries the black box warning. There are other categories of medications available to treat symptoms that do not carry this warning. Each person responds differently to medications, so it is important to speak to a psychiatrist about what medications would be helpful for your loved one.

- 10. Isn't it true that they are working on a vaccination for FTD?**

This is not true.

- 11. Our family member has FTD and has been taking Aricept and Namenda for 4-5 years now. What are your thoughts on continuing or stopping these medications? The patient was diagnosed around 2007 but symptoms started about summer 2004. She now resides in an Alzheimer's assisted living facility and rarely initiates conversation and needs assistance with most activities of daily living.**

There is no indication for these medications in FTD. It is reasonable to consider slowly tapering off these medications under physician supervision and monitoring the response.

- 12. My mom is taking wellbutrin for depression but it appears that an SSRI may be more beneficial for her PPA. Would it cause way more trouble than it's worth to change medications at this point? Wellbutrin seems to help with depression and we see very little apathy.**

Wellbutrin is a reasonable choice, if your mom is doing well on it, there is no compelling reason to change.

- 13. Dr. Reed – Lithium has tremendously helped my husband's mood swings and hyper-religiosity. Anti-depressants worsened his mood swings. Why did you not mention lithium in your talk?**

Lithium is less commonly used in FTD, likely in part due to its side effect profile. For certain symptoms it is not unreasonable to try it.

- 14. Are there any pharmaceutical companies involved in research of PPA?**

Currently, there are no drug companies that are specifically targeting PPA. This is mostly due to the fact that the changes to the brain cells in PPA have a variety of different causes, and do not all respond to treatment in the same way. However, there are some drug trials in the early stages that may include certain specific PPA patients that have known mutations or family history.