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## In The Spotlight

By Debbie L. Sklar

### Learning About Alzheimer's Disease Through New Program

Alzheimer's disease is one of those illnesses that cannot be stalled or cured until the people researching the disease conduct more studies. But there might be some light at the end of the tunnel.

Introducing UCI Health's UCI Mind program, Orange County's only state and federally funded Alzheimer's disease and research center. It recently launched a new program that gives Orange County community members a way to help. The organization has created a new registry called "Consent 2 Contact" or C2C through which anyone 18 or older can register to find out more about studies being conducted to help find a cure.

We recently talked with Steve O'Leary, 69, who shared his own personal experience and thoughts about the program.

Q: When was your wife diagnosed with AD?

A: My wife was diagnosed with Mild Cognitive Impairment in 2010 and Alzheimer's disease in 2012. Her testing and initial treatments were through UCLA and then eventually through UCI.

Q: What was your first reaction?

A: We were scared and afraid of what the Alzheimer's diag-



Steve O'Leary

nosis meant. As we started to let people know, it felt like it was a death sentence. People were shocked and often cried when we told them, especially those who had experience with the disease. There is so much fear surrounding this disease, but there is no true pattern to its progress. Some people can live several years with the disease, and others just a few.

Q: What is the C2C Registry?

A: The C2C Registry is an opportunity for people to register and then possibly volunteer for a clinical study that might help find a cure for Alzheimer's, dementia and other related diseases. Registry enrollees provide medical history and information, and UCI researchers will contact the enrollee regarding studies that are a match. It is ultimately the enrollee's choice whether he or she participates.

Q: Why did you become part of the C2C Registry?

A: I found out that the need for participants in clinical trials is dire. The lack of volunteers for studies is frankly delaying the opportunity to find prevention or cure for Alzheimer's disease. Based on that insight, I realized that joining the registry and being willing to take part in clinical trials was the most significant thing I could do to help.

Q: How did you find out about the C2C Registry?

A: I read about the C2C Registry in the UCI MIND newsletter, and then I went to the UCI MIND website at [www.c2c.uci.edu](http://www.c2c.uci.edu) to learn more.

Q: Have you participated in any research studies since you signed up for the C2C Registry?

A: I recently participated in a research study for Tinnitus, a test that looked at how my brain responded to sound. I am scheduled to be tested for UCI MIND's A4 study, which will evaluate whether treatment with a specific drug can delay or prevent the onset of cognitive decline from Alzheimer's disease.

Q: What advice do you have for others who might have family members who are suf-

fering from AD or have recently been diagnosed?

A: My advice is: Open yourself up to assistance from others, both for you and for your spouse. Get into some form of a testing process at UCI MIND or another facility to determine the level of memory lost. Find a support group for both you and your spouse, and participate actively. Work with your family members to help them better understand and deal with the disease. Have patience. You can only do what you can. It's easy to feel all sorts of emotions from anger to guilt. Live in the moment. Don't live in the past and don't try and project the future. By living in the moment, you can help your family member and yourself make it through.

Q: How can people sign up for the C2C Registry?

A: Anyone over the age of 18 can sign up at [www.c2c.uci.edu](http://www.c2c.uci.edu). Adults can provide contact information to receive updates about studies in general, or provide information about themselves and their health to be matched with studies most appropriate for them.

Q: Do you have anything else that you would like to add about the C2C Registry?

A: The C2C Registry is the most important program being

undertaken to fight dementia and Alzheimer's disease in Orange County and for that matter in Southern California. Without enough people willing to become a part of a clinical study, finding a cure will take three or four times longer than it should. This means a great deal of pain and suffering for people diagnosed with the disease, as well as their family members.

Q: What do you like to do in your spare time, any hobbies?

A: Photography, golf, and community service.

Q: What do you do for a living?

A: I work in the advertising business. I am the vice chairman of an advertising agency with offices in Newport Beach; Columbus, Ohio; New York City; and Colorado Springs. I serve on my church Vestry and manage the homeless outreach program for our parish.

