

THE DOCTOR WEIGHS IN

An Important Conversation about Alzheimer's Disease

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I was privileged to participate in an important international meeting about Alzheimer's held in Lausanne, Switzerland in October 2016. The formal title of the meeting was

"The Road to 2025: Delivering Next Generation Alzheimer Treatments."

Informally, it is known as Lausanne III because it is the third annual meeting held under the auspices of the Organization for Economic Cooperation and Development (OECD) and supported by the State Secretariat for Education, Research, and Innovation (SERI) of Switzerland, the Global CEO Initiative on Alzheimer's Disease (CEOi), and Alzheimer's Disease International (ADI). [George Vradenburg](#), Chairman and Founding Board member of UsAgainstAlzheimer's, was the convener of the meeting.

Collaboration

The goal of the meeting was to increase understanding and collaboration between the pharmaceutical industry, healthcare regulators, and payers. I was one of the participants on the Payer panel. Other participants included high-level governmental agency directors, regulators—including a former director of

the U.S. Food and Drug Administration, Alzheimer's researchers, representatives from pharmaceutical companies with Alzheimer's drugs in various stages of development, and, most importantly, people living with Alzheimer's.

A number of the speakers related their own personal stories. Tania Dussey-Cavassini, Vice-Director General of the Swiss Federal Office of Public Health and Ambassador for Global Health in Switzerland, set the stage by sharing the story of her mother's experience with the disease. The room was silent as we listened to her describe the heartbreak that is this disease.

Later, on a panel about supporting people living with Alzheimer's disease, we heard American journalist and author Greg O'Brien describe what it has been like to learn, in his early 60's, that he had early onset Alzheimer's, just like his mother and his grandfather. Now, with moderate Alzheimer's, he told us that he needs his notes to tell his story. His memory has dimmed a bit but his eloquence and story-telling were magnificent. The room was silent as he described what it is like to lose abilities that are central to your identity. In his book, ["On Pluto: Inside the Mind of Alzheimer's,"](#) he describes it like this:

"Words are the core of my life, and they are now lost on me at times. I often transpose words in what some medical professionals call an 'attentional dyslexia'....I think of my brain today, once a prized possession as an iPhone: still a sophisticated device, but one that freezes up, shuts down without notice, drops calls, pocket dials with random or inappropriate conversation, and has a small battery that takes forever to charge."

Hilary Doxford, a Brit who describes herself as a person living with dementia, is a patient activist and member of the [World Dementia Council](#). Although Hillary still has a full-time job, she is a frequent speaker at Alzheimer's events. She was accompanied to this event by her husband Peter Paniccia (aka "Peter Pan") who is a professional photographer and served as the photographer for the event. She is currently trying to organize a group of people with dementia who can serve as speakers and educators at other events.

Although there was a strong emphasis on getting new and more effective drugs into the hands of patients, Nigerian Chief Kikelomo (Kiki) Laniyonu Edwards, also a member of the World Dementia Council, reminded us that in some places in Africa, the needs are more basic. People with Alzheimer's in her

country may be considered witches. They are chained to trees and starve to death unless they are hidden from view by their loved ones. Kiki challenged the group to craft solutions that will work in places with limited resources, such as Africa, not just Europe or North America.

Learning from other diseases

Therapeutic advances in the area of HIV and cancer has been astonishing. HIV went from a rapidly fatal disease when I was in practice in San Francisco (ground zero for the epidemic) to now being, by and large, a manageable chronic condition. Similarly, new cancer therapeutics have radically transformed the course of certain cancers, including some that were inevitably fatal in the not too distant past. The former director of the National Cancer Institute and former Commissioner of the FDA, Andrew von Eschenbach, provided lessons from Oncology and Veronica Miller, Executive Director of the Forum for Collaborative HIV Research, did the same for HIV/AIDS. Differences in funding and patient activism were highlighted as some of the reasons why Alzheimer's has not seen the same types of advances in therapeutics.

Advances in drug development

Although we have not had new drugs for Alzheimer's for almost a decade, and the ones that we do have are marginally effective for symptoms and not for halting the progression of the disease, the good news is that there are now more than 70 drugs in the Alzheimer's pipeline. But the bad news, just announced a week or so ago, is that one of these new drugs, Lilly's [Solanezumab](#), failed to show a statistically significant slowing of cognitive decline in patients with early Alzheimers when compared to patients treated with placebo. Because Solanezumab's mechanism of action is to clear amyloid proteins from the blood and cerebrospinal fluid so they cannot go on to form plaques in the brain, some, but not all, experts have speculated that failure of this drug may call into question the causal relationship between amyloid plaque and the symptoms of the disease.

Barriers to getting drugs to market

In anticipation of a wave of new Alzheimer's drugs hitting the market in the next few years, the last part of the conference focused on regulatory challenges

to getting drugs approved in a timely fashion as well as preparing for payer decisions regarding coverage of what will probably be quite expensive drugs.

Former Commissioner of the U.S. FDA Andrew von Eschenbach and Rachelle Doody, the new Global Head of Neurodegeneration for Roche, framed the issues and an international group of panelists responded. In general, there was a sense that regulatory barriers were not insurmountable to rapid approval of safe and effective drugs.

The final panel focused on what type of evidence payers would need in order to support coverage of new Alzheimer's drugs. The participants from the U.S. [I was one as was Shari Ling, Deputy Chief Medical Officer, Center for Clinical Standards and Quality, at the Centers for Medicare and Medicaid Services (CMS)] explained the process CMS and plans use to make coverage determinations. The drugs must be shown to bring meaningful benefit beyond what currently exists and it is most helpful if there is a cost offset—that is, treated people end up consuming fewer healthcare resources than those who are not treated. Our European counterparts, all with government-funded national health programs said simply, if the drug is shown to work, it will be covered.

The bottom line

Lausanne III brought together some of the best minds in the field of Alzheimer's to exchange ideas and report progress on reaching the goal of stopping Alzheimer's by 2025. The collaboration and creativity of the group were apparent from the opening of the meeting until the close. Although we still have quite a way to go to answer the really big questions in this disease (what causes it and what can stop or prevent it), the sheer brainpower and passion of the group are certain to keep the needle moving in the right direction.

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