

Angioma Alliance National Patient Meeting:
Taking Charge: Living Your Best Life to Improve CCM Outcomes
DoubleTree by Hilton, Silver Spring, MD
November 8-9, 2019

This agenda is subject to change. We will update as needed.

Day 1 | Friday, November 8th

- 8:00 Registration and Breakfast. View Research Posters.
- 8:30 Amy Akers, Ph.D. Angioma Alliance Chief Scientific Officer. *Welcome & Introduction.*
- 8:40 (With researchers) Issam Awad, MD, MSc FACS, John Harper Seeley Professor of Neurosurgery and Director of Neurovascular Surgery at the University of Chicago. *Scientific Meeting 15th Anniversary Keynote Presentation.*
- 9:30 Break with Researchers and end of Poster Session
- 9:45 Reconvene in Patient Conference Room
- 9:50 Connie Lee, Psy.D., Angioma Alliance President and CEO: *Welcome and Introduction to Patient Conference.*
- 10:00 Min Park, MD, University of Virginia Department of Neurosurgery
Introduction to Cavernous Angioma: Clinical Decision-Making and Neurosurgery (plus information on Vitamin D)
- 10:40 Atif Zafar, MD, University of New Mexico Department of Neurology, *Cavernous Angioma Co-Morbidities (plus research information on sleep and hypoxia related to CCM)*
- 11:15 Tim Considine, Recursion Pharmaceuticals: *Update on REC-994 (tempol) Trial Progress*
- 11:35 Tracey Clayton, Recursion Pharmaceuticals: *CCM-Health Index*
- 11:45 Lunch (with researchers)
- 1:00 Mark Kahn, MD, University of Pennsylvania: *Recent Microbiome Research Progress*

- 1:30 Video: *Road to Recovery*
- 1:40 Diane Darcy, RD. CCM-Healthy Diet: *Protecting Gut Lining and Reducing Inflammation*
- 2:15 Kimberly Foley, MD: Pulmonologist and Angioma Alliance Board of Directors: *Diagnosing and Treating Sleep Disorders*
- 2:45 Break (with researchers)
- 3:15 Amy Akers, Ph.D., Angioma Alliance Chief Scientific Officer: *Everything You Wanted to Know About Research and Treatment Progress*
- 4:00 Conversation groups, Session 1: we'll break into facilitated small groups based on shared roles/involvement (people with brainstem lesions, seizure, familial CCM, post-surgical, caregivers/parents) to share experiences and coping strategies. Conversation groups will be held again on Saturday to allow attendees to join more than one group and/or share more in-depth.
- 5:15 End of the day
- Dinner On your own. We have a local restaurant list for attendees who would like to arrange to eat together. The hotel also has restaurants - Sergio's (Italian) and Savor (American).

Day 2 | Saturday, November 9th

- 8:00 Breakfast
- 8:30 Kristen Dahlem, RN, Angioma Alliance Clinical Research Specialist: *What Our Community Looks Like: Learnings from the Patient Registry*
- 8:50 Panel Discussion To Be Announced
- 9:30 Panel Discussion To Be Announced
- 10:00 Break
- 10:15 Connie Lee, Psy.D., Angioma Alliance President and CEO: *Moving Forward, Staying Connected (and Ask Me Anything)*
- 11:00 Conversation Groups, Session 2
- 12:30 End