

Angioma Alliance National Patient Meeting
DoubleTree by Hilton, Silver Spring, MD
November 9-10, 2018

Day 1 | Friday, November 9th

- 8:00 Registration and Breakfast
- 8:30 Welcome & Introduction
- 8:40 (With researchers) Rustam Al-Shahi Salman, MA(Cantab) MB BChir PhD MRCP(UK), University of Edinburgh Professor of Clinical Neurology. *Keynote Presentation.*
- 9:30 Break
- 9:50 Welcome to Patient Conference – Connie Lee
- 10:00 Yashar Kalani, MD, PhD, University of Virginia Department of Neurosurgery
Introduction to Cavernous Angioma: Clinical Decision-Making and Neurosurgery.
- 10:50 Kelly Flemming, MD, Mayo Clinic Department of Neurology, *Cavernous Angioma Co-Morbidities.*
- 11:45 Lunch (with researchers)
- 12:30 Lunch speaker: Dr. Issam Awad, MD MSc, University of Chicago Department of Neurosurgery, Chair of the Angioma Alliance Scientific Advisory Committee. *Context and Collaboration.*
- 1:00 Matt Abbinanti, BioAxone BioSciences. *Drug Development Pathway: a role for the Angioma community*
- 1:45 Tim Considine, Recursion Pharmaceuticals. *The REC-994 (Tempol) Story.*
- 2:30 Connie Lee, Psy.D. Angioma Alliance President & CEO. *Clinical Care and Patient Support: Raising the Bar.*
- 3:00 Break (with researchers)

3:20 Amy Akers, Ph.D., Angioma Alliance Chief Scientific Officer: *Research participation & clinical trials - without you, there can be no cure!*

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 two restaurants, Sergio's (Italian) and Savor (American).

Day 2 | Saturday, November 10th

8:00 Breakfast

8:30 Stephanie Alband, MSBA, Angioma Alliance Director of Development. *Increasing Visibility of a Mostly Invisible Illness Together.*

9:00 Stacy Suskauer, MD, Associate Professor of Physical Medicine and Rehabilitation and Pediatrics at the Johns Hopkins University School of Medicine. *Recovery and Rehabilitation: The Latest News on Getting Better.*

9:45 Cari Sullivan, Physical Therapist, Kennedy Krieger Institute. *Post-Hemorrhage and Post-Surgical Physical Therapy.*

10:30 Break

10:45 Robyn Brickel, MA, LMFT, Therapist, Brickel and Associates. *Self-care.*

11:30 Connie Lee. *Moving Forward, Staying Connected.*

11:45 Conversation Groups, Session 2

1:00 End