

Thursday, June 28th

AGENDA

1:00 – 4:00 pm
Grand Peninsula Foyer

Early Registration

2:00 – 8:00 pm
Grand Peninsula D

CSL Behring’s 11th Annual Walk for Breath Celebration

Friday, June 29th

8:30 – 10:00 am
Grand Peninsula
Ballroom ABCD

Breakfast sponsored by **Shire** with Caricature Sketch Artists

12:00 - 1:30 pm
Grand Peninsula
Ballroom ABCD

Luncheon sponsored by **Grifols - Alpha-1, Super Star of Modern Medical Genetics**
Robert A. Fallat, MD, Pulmonology, Retired

1:30 – 2:00 pm
Sequoia A

Conference Orientation for First Time Attendees
Cathey Horsak, Director of Community Programs, Alpha-1 Foundation

2:00 – 3:30 pm
Grand Peninsula
Foyer

Community Engagement Forum & Ice Cream Social

2:00 – 3:30 pm
Harbour Room

Poster Session on Current Alpha-1 Research
Adam Wanner, MD, Scientific Director, Alpha-1 Foundation

Track 1
Sequoia A

Track 2
Cypress

3:45 – 4:30 pm

Driving New Therapies and Tools in Alpha-1 – Presentation & Panel Discussion

Moderator: Jean-Marc Quach, President & CEO, The Alpha-1 Project (TAP)
Linda Neuman, MD, Adverum Biotechnologies
Bruce Given, MD, Arrowhead Pharmaceuticals

Alpha-1 Antitrypsin Deficiency 101 Lung

Jeanine M. D’Armiento, MD, PhD, Associate Professor of Medicine in Anesthesiology; Director, Center for Molecular Pulmonary Disease in Anesthesiology and Physiology and Cellular Biophysics; Director, Center for LAM and Rare Lung Disease

4:35 – 5:20 pm

Driving New Therapies and Tools in Alpha-1 – Presentation & Panel Discussion

Repeat Session

Moderator: Jean-Marc Quach
Linda Neuman, MD
Bruce Given, MD

Alpha-1 Antitrypsin Deficiency 101 Liver

Jeffrey H. Teckman, MD, Professor of Pediatrics and Biochemistry Molecular Biology; Director of Pediatric Gastroenterology and Hepatology, St. Louis University School of Medicine; Cardinal Glennon Children’s Medical Center

6:00 – 8:00 pm
Grand Peninsula

Hospitality Receptions: CSL Behring, Grifols & Shire

8:00 – 9:30 pm
Grand Peninsula

Dessert and Awards

AGENDA

Saturday, June 30th

7:30 – 8:15 am
The Grove

Breakfast & Exhibits

8:30 – 8:45 am
Grand Peninsula

Welcome

Gordon E. Cadwgan, PhD, Chair of the Board, Alpha-1 Foundation

8:45 – 9:30 am
Grand Peninsula

KEYNOTE - Patients as Partners: Having A Seat at the Table

Margaret Anderson, Managing Director, Deloitte Consulting LLP
(Previously Executive Director of FasterCures)

9:30 – 10:00 am
Grand Peninsula

Alpha-1 Foundation: Driving the Mission

Henry R. Moehring, MBA, President & CEO, Alpha-1 Foundation

10:00 – 10:15 am

Break

10:15 – 11:15 am
Grand Peninsula

Alpha-1 Research Panel

Moderated by: Robert A. Sandhaus, MD, PhD, FCCP
Mark L. Brantly, MD
Jeanine M. D'Armiento, MD
Charlie Strange, MD
Jeffrey H. Teckman, MD
Martin R. Zamora, MD

11:15 – 12:00 pm
Grand Peninsula

Presenting Sponsor Presentations: CSL Behring, Grifols, Shire

12:00 – 1:00 pm
The Grove

Meet the Speakers

1:00 – 2:00 pm
The Grove &
Regency Ballroom

Lunch & Exhibits

2:00 - 5:05 pm

Afternoon Breakout Sessions

2:00 – 4:00 pm
Cypress A

Nurse Program: Alpha-1 Antitrypsin Deficiency and Augmentation Therapy

AlphaNet is pleased to offer a free educational program for nurses, presented by Teresa Kitchen, RN, BSN, Clinical Nurse Manager. Three (3) CEU credits will be offered for nurses participating in this program.

7:00 – 9:30 pm
Grand Peninsula

Dinner & Awards

Sunday, July 1st

7:30 - 9:30 am
The Grove

Breakfast

8:30 – 9:30 am
Cypress ABC

Memorial Service

AFTERNOON BREAKOUT SESSIONS

	Track 1 Grand Peninsula EFG	Track 2 Grand Peninsula D	Track 3 Grand Peninsula ABC	Track 4 Sequoia A
2:00 – 2:30 pm	Nutrition for Advanced Lung Disease Peggy Dai, MPH, RDN, CNSC, Senior Clinician Dietitian, UCLA Ronald Reagan Medical Center	Alpha-1 Liver Disease in Adults Philip Rosenthal, MD, Professor of Pediatrics & Surgery, University of California, San Francisco	Public Policy Update Johanna Gray, Senior Vice President, CRD Associates	Understanding Your Genetic Testing Kimberly Foil, MS, CGC, Certified Genetic Counselor, Alpha-1 Foundation Genetic Counseling Program
2:35 – 3:05 pm	Sex Spoken Here: Intimacy and the Patient with Chronic Illness Deborah Fending, RN, BSN, AE-C, Staff Development Nurse, National Jewish Health	Preventions & Treatment Strategies for Alpha-1 Individuals Mark L. Brantly, MD, Vice Chair of Research, Department of Medicine, Professor of Medicine, Molecular Genetics and Microbiology; Alpha-1 Foundation Research Professor, University of Florida College of Medicine	Access & Reimbursement Panel of Experts Johanna Gray (Moderator) Barbee Bennington, Support Group and Program Coordinator, Alpha-1 Foundation Angela Merkens, Volunteer Alpha-1 Support Group Leader	Basics of Alpha-1 Liver Disease in Children Philip Rosenthal, MD, Professor of Pediatrics & Surgery, University of California, San Francisco
3:05 – 3:25 pm	BREAK & EXHIBITS			
3:25 – 3:55 pm	Pulmonary Rehabilitation Update Chris Garvey, FNP, MSN, MPA, MAACVPR, UCSF Sleep Disorders and Pulmonary Rehabilitation	Anxiety & Depression Kristen Holm, PhD, MPH, Assistant Professor, National Jewish Health	Improving Access to Supplemental Oxygen Susan Jacobs, RN, MS, Clinical Research Nurse Manager, Pulmonary and Critical Care Medicine; Nurse Coordinator, Center for Advanced Lung Disease, Stanford University Medical Center	Managing Alpha-1 Liver Disease in Children Philip Rosenthal, MD, Professor of Pediatrics & Surgery, University of California, San Francisco
4:00 – 4:30 pm	Update on Lung Transplantation for Alpha-1 Steven R. Hays, MD, Professor of Medicine, Medical Director of Advanced Lung Disease & Lung Transplant Program, University of California, San Francisco	Importance of Clinical Trials and Participation Charlie Strange, MD, Professor of Pulmonary Medicine, Medical University of South Carolina (MUSC)	Traveling with Alpha-1 Skip Scribner, President, Advanced Aeromedical	There Will Be Stress: Keeping a Lid on the Negative Impacts of Alpha-1 Caregiving & Getting Bonnie Chakravorty, MSW, PhD, Retired Professor, Tennessee State University; Board Member, AlphaNet
4:35 – 5:05 pm	Replacement Therapy After Lung Transplantation? Martin R. Zamora, MD, Professor of Medicine, Division of Pulmonary Sciences and Critical Care Medicine; Medical Director of Lung Transplantation, University of Colorado	Conditions Associated with Alpha-1 Robert A. Sandhaus, MD, PhD, FCCP, Clinical Director, Alpha-1 Foundation; Executive Vice President and Medical Director, AlphaNet; Professor of Medicine, National Jewish Health	Social Media Do's/Don'ts & Making Connections Alexis Artiles, Director of Marketing & Events Maria Virginia Deliz, Digital Media Manager, Alpha-1 Foundation	Creating a Healthy Home while Living with COPD Miguel Villarreal, BS, MLS/MT, LVN, Clinical Research Coordinator II, UCLA David Geffen School of Medicine