

# Agenda

Thursday, June 22<sup>nd</sup>

2:00 – 5:00 pm  
Tate Foyer

**Early Conference Registration**

3:00 – 8:00 pm  
Pollock

**CSL Behring's 10th Annual Walk for Breath Celebration**

Friday, June 23<sup>rd</sup>

8:00 – 10:00 am  
Cassatt

Breakfast sponsored by **Shire**

12:00 - 1:30 pm  
Cassatt

Lunch sponsored by **Grifols**  
**Speaker:** Richard Lovrich, Photographer, Writer & Advocate

1:30 – 2:00 pm  
Warhol

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

**Track 1**  
Warhol

**Track 2**  
Pollock

2:10 – 3:00 pm

**Alpha-1 Antitrypsin Deficiency 101 Lung**  
D. Kyle Hogarth, MD, FCCP, Associate Professor of Medicine, Director of Bronchoscopy, Director: Alpha-1 Clinical Resource Center, University of Chicago

**Clinical Trial Design**  
Mark L. Brantly, MD, Professor of Medicine and Chief, Molecular Genetics and Microbiology, Division of Pulmonary, Critical Care & Sleep Medicine, University of Florida College of Medicine

3:10 – 4:00 pm

**Alpha-1 Antitrypsin Deficiency 101 Liver**  
Virginia "Ginger" Clark, MD, Associate Program Director, Transplant Hepatology Fellowship; Assistant Professor of Medicine, Division of Gastroenterology, Hepatology, and Nutrition, University of Florida

**Clinical Trials & Participation**  
D. Kyle Hogarth, MD, FCCP

2:00 – 6:00 pm  
Metropolitan

**Meet the Experts**

4:00 – 6:00 pm  
Montrose

**Community Engagement Forum & Ice Cream Social**  
Meet the community leaders: AlphaNet Coordinators, Support Group Leaders & Alpha-1 Foundation Staff. Learn about Alpha-1 Young Adults, Alpha-1 Global, Building Friends for a Cure, Caregivers & Access and Reimbursement  
**Workshop:** How to Tell Your Alpha-1 Story

6:00 – 8:00 pm  
Cassatt

**Hospitality Suite Receptions: CSL Behring, Grifols & Shire**

8:00 – 9:30 pm  
Cassatt

**Dessert and Awards**

9:30 – Midnight  
Montrose

**Club Alpha: Socializing and music**

# Agenda

## Saturday, June 24<sup>th</sup>

7:00 – 8:00 am Artist Foyer	<b>Breakfast</b>
8:00 – 8:15 am Cassatt	<b>Welcome</b> Gordon E. Cadwgan, PhD, Chair of the Board, Alpha-1 Foundation
8:15 – 8:45 am Cassatt	<b>Alpha-1 Foundation Welcome &amp; Update</b> Henry R. Moehring, MBA, President & CEO, Alpha-1 Foundation
8:45 – 9:30 am Cassatt	<b>Keynote: The NIH and its Role in the Alpha-1 Community</b> James P. Kiley, BS, MS, PhD, Director, Division of Lung Diseases, NHLBI
9:30 – 10:30 am Cassatt	<b>Alpha-1 Research Panel</b> Moderated by Adam Wanner, MD, Scientific Director, Alpha-1 Foundation Mark L. Brantly, MD Jeanine M. D'Armiento, MD, PhD D. Kyle Hogarth, MD, FCCP Jeffrey Teckman, MD
10:30 – 10:45 am	<b>Break</b>
10:45 – 11:30 am Cassatt	<b>Platinum Sponsor Presentations: CSL Behring, Shire &amp; Grifols</b>
11:30 – 12:15 pm Cassatt	<b>The Alpha-1 Project Panel</b> Moderated by Jean-Marc Quach, President and CEO of The Alpha-1 Project Samuel B. Barone, MD, Senior Vice President, Clinical Development, Adverum David Miller, PhD, Senior Vice President, Corporate Operations, Dicerna Mike Iannotti, PhD, Postdoctoral Research Fellow, Laboratory of Assay Development & Screening Technology, National Center for Advancing Translational Sciences, National Institutes of Health Terence R. Flotte, MD, Celia and Isaac Haidak Professor in Medical Education, University of Massachusetts Medical School (UMMS); Professor of Pediatrics, Horae Gene Therapy Center
12:15 – 1:00 pm Artist Foyer	<b>Meet the Speakers</b>
1:00 – 2:00 pm Artist & Avedon	<b>Lunch &amp; Exhibits</b>
2:00 - 5:05 pm	<b>Breakout Sessions</b>
2:00 – 4:00 pm Prado	<b>Nurse Program: Alpha-1 Antitrypsin Deficiency and Augmentation Therapy</b> 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 – 10:00 pm Cassatt	<b>John W. Walsh Tribute Dinner</b>

## Sunday, June 25<sup>th</sup>

8:00 – 9:30 am Cassatt	<b>Breakfast</b>
8:30 – 9:30 am Pollock	<b>Memorial Service</b>

# Afternoon Breakout Sessions

	Track 1 Cassatt C	Track 2 Cassatt A & B	Track 3 Cassatt D	Track 4 Pollock
2:00 – 2:40 pm	<p><b>What's New in Treatments and Does Treatment Work?</b></p> <p>Robert A. Sandhaus, MD, PhD, FCCP, Clinical Director, Alpha-1 Foundation; Executive Vice President and Medical Director, AlphaNet; Professor of Medicine, National Jewish Health</p>	<p><b>Music Therapy - The Role of Music in Pulmonary Rehab</b></p> <p>Wills McKenna, MS, MT-BC, Board-Certified Music Therapist</p>	<p><b>Insurance: Back to Basics</b></p> <p>Catherine Blansfield, MA, BS, RN, Vice President of Patient Services, National Organization for Rare Disorders (NORD)</p>	<p><b>Genetics &amp; Importance of Family Testing</b></p> <p>Kim Brown, CGC, Genetic Counselor, Alpha-1 Foundation Genetic Counseling Program</p>
2:45 – 3:25 pm	<p><b>Transplant Policies &amp; Procedures</b></p> <p>Kamyar Afshar, DO, University of California, San Diego, Center for Advanced Lung Disease</p>	<p><b>Maintaining Intimacy &amp; Healthy Relationships Alongside Chronic Illness</b></p> <p>Deborah Fending RN, BSN, AE-C, National Jewish Health</p>	<p><b>Public Policy Concerns &amp; Opportunities</b></p> <p>CRD Associates: Lyle Dennis, Partner Johanna Gray, Senior Vice President Erika Miller, Senior Vice President and Counsel</p>	<p><b>Pediatric Liver Disease Update</b></p> <p>Jeffrey 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</p>
3:25 – 3:40 pm	<b>BREAK &amp; EXHIBITS</b>			
3:40 – 4:20 pm	<p><b>What Does it Mean to be an Alpha-1 Carrier? (MS, MZ, MF, etc.)</b></p> <p>Charlie Strange, MD, Professor of Pulmonary Medicine, Medical University of South Carolina</p>	<p><b>Using Technology to Track &amp; Manage Wellness</b></p> <p>Mark Lightowler, Founder and CEO at Phorix Limited</p>	<p><b>Anxiety &amp; Depression in the Alpha-1 Community</b></p> <p>Lindsay Brauer, PhD, Department of Psychiatry and Behavioral Neuroscience, University of Chicago</p>	<p><b>Caregiving Strategies &amp; Caregiver Workshop</b></p> <p>Mark Gibbons, Director of Operations and Programs, Caregiver Action Network</p>
4:25 – 5:05 pm	<p><b>Benefits &amp; Cautions of Using Social Media</b></p> <p>Alexis Artiles, Marketing &amp; Events Manager Maria Virginia Deliz, Communications Coordinator Alpha-1 Foundation</p>	<p><b>The Importance of Exercise</b></p> <p>Sarah Volk, BS, RRT, Cpft, AE-C</p>	<p><b>A Patients Role in End of Life Choices</b></p> <p>Teresa Kitchen, RN, BSN, Clinical Nurse Manager, AlphaNet</p>	