

## 24<sup>th</sup> Annual National Education Conference Agenda

July 24 – 26, 2015 • Hyatt Regency Orange County • Garden Grove, CA

Thursday, July 23		
2:00 – 5:00 pm Hotel Foyer	Early Conference Registration	
3:00 – 8:00 pm	<b>CSL Behring's 8<sup>th</sup> Annual Walk for Breath Celebration</b> Registration: Grand Ballroom Foyer A	
Friday, July 24		
8:00 – 10:00 am Grand Ballroom A	Cartoon Character Breakfast sponsored by <b>Baxalta</b>	
12:00 - 1:30 pm Grand Ballroom A	Lunch sponsored by <b>Grifols</b> Guest Speaker: Jonathan Maidment, Hiking for a Cure	
9:00 am – 5:00 pm Hotel Foyer	Registration Hours	
1:30 – 6:00 pm Royal Ballroom	Exhibit Hall Hours	
	Track 1 – Garden 4	Track 2
2:00 – 4:00 pm	<b>Meet the Experts</b> Registration available for questions with Clinical Resource Center doctors. <ul style="list-style-type: none"> <li>• Alan Barker, MD</li> <li>• Mark Brantly, MD</li> <li>• Michael Campos, MD</li> <li>• Ginger Clark, MD</li> <li>• James Donohue, MD</li> <li>• Robert A. Sandhaus, MD, PhD</li> <li>• Ron Sokol, MD</li> <li>• Charlie Strange, MD</li> <li>• Jeffrey Teckman, MD</li> </ul>	<b>Community Forum (Garden 1 &amp; 2)</b>  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, Patient Assistance and more.
4:10 – 5:00 pm	<b>Alpha-1 Antitrypsin Deficiency 101: Lung</b> Kamyar Afshar, DO, USC, Keck School of Medicine	<b>The Alpha-1 Project (Garden 3)</b> Jean-Marc Quach, Executive Director, The Alpha-1 Project
5:10 – 6:00 pm	<b>Alpha-1 Antitrypsin Deficiency 101: Liver</b> 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	<b>Patient Centered Research, What We Do &amp; Where You Fit In (Garden 3)</b> Robert A. Sandhaus, MD, PhD, FCCP, Clinical Director, Alpha-1 Foundation, Executive Vice President, AlphaNet, Professor of Medicine, National Jewish Health

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6:00 – 8:00 pm Grand Ballroom	<b>Hospitality Suite Receptions</b> Baxalta – BCD CSL Behring - A Grifols - EFG
8:00 – 9:30 pm Grand Ballroom	Dessert Hour and Awards
9:30 – Midnight Garden 3	Club Alpha: Socializing and music
<b>Saturday, July 25</b>	
7:30 – 8:15 am Terrace Rooms	Breakfast
7:30 – 5:00 pm Royal Ballroom	Exhibit Hall Hours
8:30 – 8:45 am Grand Ballroom	<b>Welcome and Opening Remarks</b> John W. Walsh, Co-Founder, President and CEO of Alpha-1 Foundation
8:45 – 9:30 am Grand Ballroom	<b>Educate + Engage + Empower = ACTION</b> Miriam O'Day, Consultant, National Organization for Rare Disorders (NORD); former Alpha-1 Foundation Senior Director of Public Policy
9:30 – 10:15 am Grand Ballroom	<b>20 Years of Successes - Alpha-1 Foundation Research Update</b> John W. Walsh, Co-Founder, President and CEO of Alpha-1 Foundation
10:15– 10:45 am Grand Ballroom	Presenting Sponsor Presentations: Baxalta, CSL Behring, Grifols
10:45– 11:30 am Grand Ballroom	<b>20 Years of Successes - AlphaNet Health Management Program</b> Robert A. Sandhaus, MD, PhD, FCCP, Clinical Director, Alpha-1 Foundation, Executive Vice President, AlphaNet, Professor of Medicine, National Jewish Health
11:30 - 12:15 pm Grand Ballroom	<b>Alpha-1 Liver Research Update Panel</b> <ul style="list-style-type: none"> <li>• <b>Adam Wanner, MD</b>, Scientific Director, Alpha-1 Foundation - Moderator</li> <li>• <b>Jeffrey Teckman, MD</b>, Professor of Pediatrics and Biochemistry &amp; Molecular Biology, Director of Pediatric Gastroenterology and Hepatology, St. Louis University School of Medicine Cardinal Glennon Children's Medical Center</li> <li>• <b>Ron Sokol, MD</b>, Professor and Vice Chair, Section Chief, Children's Hospital Colorado and University of Colorado School of Medicine</li> <li>• <b>David Brenner, MD</b>, Vice Chancellor, Health Sciences, Dean, School of Medicine, Professor of Medicine, UC San Diego School of Medicine</li> <li>• <b>Bruce Given, MD</b>, Chief Operating Officer, Arrowhead Research Corporation</li> <li>• <b>Alpha-1 Parent and Patient</b></li> </ul>
12:15 – 1:00 pm Terrace Rooms	<b>Meet the Stars</b> Questions with the speakers/experts
1:00 – 2:00 pm Terrace Rooms	Lunch & Exhibits

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	<b>Track 1 – Grand A</b>	<b>Track 2 – Grand BCD</b>	<b>Track 3 – Grand EFG</b>	<b>Track 4 – Garden 3</b>
2:00 – 2:40 pm	<b>Genetics of Alpha-1</b>  Kim Brown, Certified Genetic Counselor, Alpha-1 Foundation Genetic Counseling Program	<b>Strategies to Improve Exercise Tolerance</b>  Richard Casaburi, MD, Professor of Medicine, UCLA School of Medicine	<b>Public Policy Update</b>  Miriam O'Day, Consultant, NORD; former Alpha-1 Foundation Senior Director of Public Policy	<b>Parent Meet &amp; Greet</b>  Sandi Ries Douglas, Alpha-1 Parent, Member of the Alpha-1 Foundation Board of Directors
2:00 – 4:00 pm Garden 4	<b>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.			
2:45 – 3:25 pm	<b>What to Expect from Your Physician</b>  Robert A. Sandhaus, MD, PhD, FCCP, Clinical Director, Alpha-1 Foundation, Executive Vice President, AlphaNet, Professor of Medicine, National Jewish Health	<b>Living Healthy, Happy &amp; Well – A Mindful Approach</b>  Penny O'Brien, MS, Director of Wellness Services, GBS Benefits, Inc	<b>Access &amp; Reimbursement</b>  Moderator: Miriam O'Day Panel of experts: Barbee Bennington, Support Group & Program Coordinator, Alpha-1 Foundation & GERALYN Molinari, Volunteer	<b>Pediatric Liver Disease</b>  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
3:25 – 3:40 pm	Break			
3:40 – 4:20 pm	<b>"I've Looked at Life from Both Sides Now..." Issues in Alpha-1 Antitrypsin Deficiency</b>  James Stoller, MD, MS, Chair, Education Institute, Cleveland Clinic Foundation, Cleveland Clinic Lerner College of Medicine	<b>Lung Transplantation – From Evaluation to Transplantation &amp; Beyond</b>  David Sayah, MD, PhD, Assistant Clinical Professor, Lung & Heart-Lung Transplant Program, UCLA	<b>Traveling with Oxygen</b>  Skip Scribner, President, Advanced Aeromedical & William "Bill" Clark, Director of Outreach Programs, COPD Foundation	<b>ChiLDREN Research Study</b>  Ron Sokol, MD, Professor and Vice Chair, Section Chief, Children's Hospital Colorado and University of Colorado School of Medicine
4:20 – 4:40 pm	Break			

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<p>4:40 – 5:05 pm Grand Ballroom</p>	<p><b>Last Chance for Questions – Physician Panel</b></p> <ul style="list-style-type: none"> <li>• <b>Robert A. Sandhaus, MD, PhD, FCCP</b>, Clinical Director, Alpha-1 Foundation, Executive Vice President, AlphaNet, Professor of Medicine, National Jewish Health - Moderator</li> <li>• <b>Charlie Strange, MD</b>, Professor of Pulmonary Medicine, Medical University of South Carolina</li> <li>• <b>James Stoller, MD, MS</b>, Chair, Education Institute, Cleveland Clinic Foundation, Cleveland Clinic Lerner College of Medicine</li> <li>• <b>Alan Barker, MD</b>, Professor of Medicine, Division of Pulmonary and Critical Care Medicine, Oregon Health &amp; Science University</li> <li>• <b>Mark Brantly, MD</b>, Professor of Medicine and Chief, Molecular Genetics and Microbiology, Division of Pulmonary, Critical Care &amp; Sleep Medicine, University of Florida College of Medicine</li> </ul>
<p>7:00 – 9:30 pm Grand Ballroom</p>	<p>Dinner &amp; Awards</p>
<p>9:30 – Midnight Garden 3</p>	<p>Club Alpha: Socializing and KARAOKE</p>
<p><b>Sunday, July 26</b></p>	
<p>7:30 - 9:30 am Grand Ballroom</p>	<p>Breakfast</p>
<p>8:30 – 9:30 am Garden 4</p>	<p>Memorial Service</p>