

## Alpha-1 National Conference Agenda

June 9-11, 2023 • Hyatt Regency DFW International Airport • Dallas, Texas

*\*The times & details on this agenda are subject to change\**

Thursday, June 8 <sup>th</sup>	
1:00 pm – 4:00 pm Enterprise Foyer	Early Conference Registration

Friday, June 9 <sup>th</sup>	
8:30 – 10:00 am Enterprise 7-8	Breakfast
9:00 am – 5:00 pm Enterprise Foyer	Registration Hours
12:30 – 5:30 pm Aviators	Exhibit Hall Hours

Track 1 Enterprise 1-2		Track 2 Enterprise 5-6	
10:00 am – 10:30 am	<p><b>Conference Orientation for First Time Attendees</b></p> <p>Cathey Henderson <i>Director of Community Programs, Alpha-1 Foundation</i></p>	10:00 am – 10:30 am	<p><b>The Alpha-1 Foundation's Research Agenda</b></p> <p>Andrew Wilson, MD <i>Scientific Director, Alpha-1 Foundation; Associate Professor of Pulmonary, Allergy, Sleep &amp; Critical Care Medicine, Boston University</i></p>
10:40 am – 11:25 am	<p><b>Alpha-1 Antitrypsin Deficiency 101 Lung</b></p> <p>Charlie Strange, MD <i>Professor, Pulmonary and Critical Care Medicine, Medical University of South Carolina</i></p>	10:40 am – 11:25 am	<p><b>Lung Imaging</b></p> <p>Mike Wells, MD <i>Assistant Professor, Pulmonary Medicine &amp; Critical Care Medicine, University of Alabama</i></p> <p><b>Liver Imaging</b></p> <p>Virginia Clark, MD <i>Program Director &amp; Associate Professor, Gastroenterology, Hepatology &amp; Nutrition Division, University of Florida</i></p>
11:35 am – 12:15 pm	<p><b>Alpha-1 Antitrypsin Deficiency 101 Liver</b></p> <p>Virginia Clark, MD <i>Program Director &amp; Associate Professor, Gastroenterology, Hepatology &amp; Nutrition Division, University of Florida</i></p>	11:35 am – 12:15 pm	<p><b>Overview of the Alpha-1 Biomarkers Consortium (A1BC) Study</b></p> <p>Jeanine D'Armiento, MD, PhD <i>Associate Professor of Medicine in Anesthesiology, Columbia University</i></p> <p>Charlie Strange, MD <i>Medical Director, AlphaNet; Professor, Pulmonary and Critical Care Medicine, Medical University of South Carolina</i></p>

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			<p>Monica Goldklang, MD <i>Assistant Professor of Medicine in Anesthesiology, Columbia University</i></p> <p>Mike Wells, MD <i>Assistant Professor, Pulmonary Medicine &amp; Critical Care Medicine, University of Alabama</i></p>
12:30 pm – 2:00 pm	<p><b>LUNCH</b> Enterprise 7-8</p>	12:30 pm – 2:00 pm	<p><b>LUNCH</b> Enterprise 7-8</p>
2:00 pm – 2:40 pm	<p><b>Clinical Trials Explained &amp; How A Therapy Comes to Market</b></p> <p>Mark Brantly, MD Professor, Department of Molecular Genetics &amp; Microbiology, University of Florida</p>	2:00 pm – 4:10 pm	<p><b>Emerging Therapies in Alpha-1</b></p> <p>Moderator: Andrew Wilson, MD <i>Scientific Director, Alpha-1 Foundation; Associate Professor of Pulmonary, Allergy, Sleep &amp; Critical Care Medicine, Boston University</i></p> <p>Moderator: Virginia Clark, MD <i>Program Director &amp; Associate Professor, Gastroenterology, Hepatology &amp; Nutrition Division, University of Florida</i></p> <p>Beam Therapeutics</p> <p>BioMarin</p> <p>Inhibrx</p> <p>Novo Nordisk</p> <p>Takeda Pharmaceuticals</p> <p>Vertex</p> <p>Wave Life Sciences</p>
4:30 – 5:30 pm Enterprise 7-8	<p><b>Alpha-1 Research Registry Celebration</b></p> <p><i>Celebrate the 3,000<sup>th</sup> person enrolled in the Alpha-1 Research Registry! Be part of the cure for Alpha-1! Learn how here...</i></p>		
5:00 – 6:00 pm Grapevine	<p><b>Alpha-1 Kids Room Meet and Greet</b></p> <p>Jeffrey Teckman, MD, <i>Patricia and James Monteleone Endowed Chair, Pediatric Gastroenterology and Hepatology, Professor of Pediatrics and Biochemistry, Saint Louis University School of Medicine, Cardinal Glennon Children's Hospital</i></p>		
6:30 – 9:30 pm Enterprise 1-6	<p><b>Western Party Dinner Reception</b></p>		

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Saturday, June 10 <sup>th</sup>	
8:00 – 9:00 am Enterprise 7-8	Breakfast
8:00 – 5:00 pm Aviators	Exhibit Hall Hours
8:00 – 2:00 pm Enterprise Foyer	Registration Hours
8:30 am – 5:00 pm Grapevine	Alpha-1 Kids Room Closed during lunch – 1:00 to 2:00 pm
9:00 – 9:15 am Enterprise 1-6	<b>Opening Remarks and Alpha-1 Foundation Address</b>  Jon Hagstrom, <i>Chair of the Board of Directors, Alpha-1 Foundation</i> Scott Santarella, <i>President &amp; CEO, Alpha-1 Foundation</i>
9:15 – 10:15 am Enterprise 1-6	<b>Alpha Empowerment Hour</b>
10:15 – 11:00 am Enterprise 1-6	<b>Platinum Sponsor Presentations</b>
11:00 – 12:00 pm Enterprise 1-6	<b>Alpha-1 Research Panel</b>  Moderated by: Andrew Wilson, MD <i>Scientific Director, Alpha-1 Foundation; Associate Professor of Pulmonary, Allergy, Sleep &amp; Critical Care Medicine, Boston University</i>
12:00 – 1:00 pm Enterprise 7-8	<b>Meet the Speakers &amp; Roundtables</b>
1:00 – 2:00 pm Enterprise 7-8	<b>Lunch &amp; Exhibits</b>

	Track 1 Enterprise 1-2	Track 2 Enterprise 3-4	Track 3 Enterprise 5-6
2:00 – 2:35 pm	<p><b>MZ Presentation</b></p> <p>Joseph Kaserman, MD <i>Assistant Professor of Medicine, Chobanian and Avedisian School of Medicine, Researcher, Wilson Lab, Boston University</i></p>	<p><b>General Patient Care &amp; Treatment as an Alpha - Questions to Ask Your Doctor</b></p> <p>Robert A. Sandhaus, MD, PhD, FCCP <i>Clinical Director, Alpha-1 Foundation; Senior Medical Director, AlphaNet</i></p>	<p><b>Genetics, Family Testing, &amp; Phenotypes</b></p> <p>Monica Goldklang, MD <i>Assistant Professor of Medicine in Anesthesiology, Columbia University</i></p>
2:40 – 3:15 pm	<p><b>Integrative Therapies</b></p> <p>Michael Campos, MD <i>Professor of Clinical Medicine, University of Miami School of Medicine</i></p>	<p><b>Regenerative Medicine: The State of the Science &amp; Tissue Regeneration</b></p> <p>Darrell Kotton, MD <i>Professor, Boston University Chobanian &amp; Avedisian School of Medicine</i></p>	<p><b>Long Term Health and Wellness for Alpha-1 Kids</b></p> <p>Dana Goldner, MD <i>Assistant Professor of Pediatrics in Pediatric Hepatology, Columbia University Medical, Assistant</i></p>

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			<i>Attending at New York-Presbyterian Morgan Stanley Children's Hospital</i>
3:15 – 3:35 pm	<b>Break</b>		
3:35 – 4:10 pm	<p style="text-align: center;"><b>Pre and Post Transplant</b></p> <p>Moderator: Lorrinda Gray Davis, President, Transplant Recipient International Organization (TRIO)</p> <p style="text-align: center;">Jon Hagstrom <i>Chair of the Board of Directors, Alpha-1 Foundation</i></p> <p style="text-align: center;">Fred Walsh <i>Alpha-1 Foundation Board Member</i></p>	<p style="text-align: center;"><b>Public Policy</b></p> <p style="text-align: center;">Scott Santarella <i>President &amp; CEO, Alpha-1 Foundation</i></p> <p style="text-align: center;"><b>Oxygen Reform Legislation</b></p> <p style="text-align: center;">Miriam O'Day <i>Senior Policy Advisor, Alpha-1 Foundation</i></p>	<p style="text-align: center;"><b>Coping with a Chronic Illness as a Parent of an Alpha-1 Kid</b></p> <p style="text-align: center;"><b>Alpha-1 Parents Panel</b></p> <p>Moderator: Dana Goldner, MD Erin Carr, Alpha-1 Parent Pam VanScoy, Alpha-1 Parent</p>
4:15 – 4:50 pm	<p style="text-align: center;"><b>Alpha-1 Advocacy Access &amp; Reimbursement</b></p> <p>Moderator: Miriam O'Day, <i>Senior Policy Advisor, Alpha-1 Foundation</i></p> <p style="text-align: center;">Jill Pollander, RN, MSN <i>Vice President of Patient Services, National Organization for Rare Disorders (NORD)</i></p> <p style="text-align: center;">Jennifer Noonan, MSN, RN <i>Senior Director, Clinical Programs &amp; Compliance, Accessia Health</i></p>	<p style="text-align: center;"><b>Current and Future Therapies in Liver Disease</b></p> <p style="text-align: center;">Jeffrey Teckman, MD <i>Patricia and James Monteleone Endowed Chair, Pediatric Gastroenterology and Hepatology, Professor of Pediatrics and Biochemistry, Saint Louis University School of Medicine, Cardinal Glennon Children's Hospital</i></p>	<p style="text-align: center;"><b>Transplants for Alpha-1 Children</b></p> <p style="text-align: center;">Nitika Arora Gupta, MD, DCH, DNB, MRCPH(UK), FAASLD <i>Professor of Pediatrics, Medical Director-Hepatology and Liver Transplant, Emory University School of Medicine, Children's Healthcare of Atlanta</i></p>
7:00 – 9:00 pm Enterprise 1-6	<b>Dinner Reception</b>		
<b>Sunday, June 11<sup>th</sup></b>			
8:00 – 9:30 am Enterprise 7-8	<b>Breakfast</b>		
8:30 – 9:30 am Enterprise 5-6	<b>Alpha Angels Memorial Service</b>		