

7th Alpha-1 Global Patient Congress Agenda

4-6 April 2019 • Sheraton Dubrovnik Riviera Hotel • Dubrovnik, Croatia

Thursday, 4 April	
1:00 – 6:00 pm Hotel Lobby Reg. Desk	Congress Registration
6:30 – 7:00 pm Piano Bar Terrace	Welcome Reception <ul style="list-style-type: none"> • Miriam O'Day, CEO, Alpha-1 Foundation • European & Croatian Representatives (TBD)
7:00 – 8:30 pm Leut Restaurant	Joint Dinner Between International Research Conference on Alpha-1 Antitrypsin & Alpha-1 Global Patient Congress Participants <ul style="list-style-type: none"> • Opportunity to meet and network with participants: patients, researchers, physicians, & industry representatives
Friday, 5 April	
7:00 – 8:45 am Leut Restaurant	Breakfast Buffet
9:00 – 9:15 am Orlando Congress Room	Welcome to the 7th Alpha-1 Global Patient Congress <ul style="list-style-type: none"> • Welcome and Emcee Introduction (Miriam O'Day) • Emcee – Set up and Announcements (Richard Lovrich)
9:15 – 9:35 pm Orlando Congress Room	Presenting Sponsors (Richard Lovrich) <ul style="list-style-type: none"> • CSL Behring and Grifols: Presenting Sponsor Introductions
9:35 – 11:20 am Orlando Congress Room 10:30 am - Coffee Service Orlando Congress Room	Research and Therapeutic Updates (<i>Adam Wanner, Chair</i>) <ul style="list-style-type: none"> • <i>Research Conference Summary & Outcomes (Rob Stockley)</i> • <i>Is the Alpha-1 MZ Carrier State Clinically Relevant (Gerry McElvaney)</i> • <i>What is Next in Therapeutic Developments (Robert Sandhaus)</i> • <i>Q & A Time</i>
11:20 am – 12:05 pm Orlando Conference Room	Physicians Education & Collaborative Efforts (Karen O'Hara) <ul style="list-style-type: none"> • ERN-LUNG – Joanna Chorostowska • EARCO - Marc Miravittles
12:05 – 1:25 pm Leut Restaurant	Lunch & Networking Time

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<p>1:25 – 1:40 pm Orlando Congress Room</p>	<p>Welcome Back</p> <ul style="list-style-type: none"> • Overview of Afternoon • Introduction of Country Representatives/Delegates (Video)
<p>1:40 pm – 3:10 pm Orlando Congress Room</p>	<p>Regional Updates (Richard Lovrich – Moderator):</p> <ul style="list-style-type: none"> • Western Europe • Southern Europe • Eastern & Central Europe • Middle East • South Pacific • South America • Africa • North America
<p>3:10 – 4:20 pm Orlando Conference Room</p> <p>3:10 pm - Coffee Service Orlando Congress Room</p>	<p>Alpha-1 Patient Engagement in Research</p> <ul style="list-style-type: none"> • Empowering the Patient (TBD) • The Impact of Participating in Clinical Research (Marion Bouchecareilh)
<p>4:20 – 4:45 pm Orlando Conference Room</p>	<p>Panniculitis (Sabina Janciauskiene - Chair)</p> <ul style="list-style-type: none"> • Sabina Janciauskiene – Physician Perspective • Heleen Groen – Patient Perspective
<p>4:45 – 5:00 pm Orlando Conference Room</p>	<p>The Young Patient Voice Interview with Richard Lovrich</p> <ul style="list-style-type: none"> • Arran Strong; Alpha/Surfer • Martina Cambon
<p>5:00 – 5:30 pm Orlando Conference Room</p>	<p>Emotional Balance: Being a Leader and a Patient (Frank Willersinn)</p> <ul style="list-style-type: none"> • Nathalie Seewer – Patient Leader and Lung Transplant Patient Perspective
<p>7:00 – 7:30 pm Piano Bar Terrace</p>	<p>Cocktail Reception - The Fifty Year Secret: An Amazing Alpha-1 Family Story</p> <ul style="list-style-type: none"> • Julie MacNeil - the importance of family testing
<p>7:30 – 9:00 pm Leut Restaurant</p>	<p>Dinner</p>

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Saturday, 6 April	
7:00 – 10:00 am Leut Restaurant	Breakfast Buffet
7:00 – 10:00 am Breakout Rooms	Country Leadership Meeting with Presenting Sponsors <ul style="list-style-type: none"> • Breakout Rooms – Adjacent to Orlando Lobby
10:00 – 10:15 am Orlando Congress Room	Good Morning (Richard Lovrich) <ul style="list-style-type: none"> • Exercise for Alphas (Karen Skålvoll)
10:15 – 11:15 am Orlando Congress Room 10:30 am - Coffee Service Orlando Congress Room	Together Building the Case for Augmentation Therapy Reimbursement <ul style="list-style-type: none"> • Current Treatment Guidelines (James Stoller) <ul style="list-style-type: none"> ○ Comparison of Guidelines Around the World • Burden of Disease (Carina Schey) <ul style="list-style-type: none"> ○ Burden to the Patient & Family/Carer ○ Clinical Burden (Healthcare Resource utilization) ○ Economic Burden (Current HTA Reality) • Health Management Outcomes (Robert Sandhaus) <ul style="list-style-type: none"> ○ AlphaNet Data, A1F Patient Polling Data, UK/US Morbidity Study, German/Italian Study, Other . . .
11:15 am – 12:30 pm Orlando Congress Room	Different Perspectives in the Provision of Treatment (Carina Schey, Chair) <ul style="list-style-type: none"> • Access Challenges to Plasma-Derived Treatment (Julie Birkofer) <ul style="list-style-type: none"> ○ Summary to Access to AT Around the World
12:30 – 1:40 pm Leut Restaurant	Lunch & Networking Time
1:40 – 2:45 pm Orlando Congress Room	Welcome Back/Presenting Sponsor <ul style="list-style-type: none"> • Welcome Back and Overview of Afternoon Panel – Open Q&A (Moderator – Richard Lovrich) <ul style="list-style-type: none"> • With speakers from <i>Together Building the Case for Augmentation Therapy Reimbursement & Different Perspectives in the Provision of Treatment</i>
2:45 – 3:15 pm Orlando Congress Room	The Importance of Advocacy and Patient Involvement in Policy (Yordan Aleksandrov) <ul style="list-style-type: none"> • RPP Update (EU Parliament Roundtable Meeting & 2nd EU Alpha-1 Advocacy Awareness Day)

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3:15 – 4:15 pm Orlando Congress Room	Leadership Panel: Ask Your Peer (Richard Lovrich – Moderator)
4:15 – 4:45 pm Orlando Congress Room	Next Steps (Speakers, Moderator - TBD)
4:45 – 5:00 pm Orlando Congress Room	Conclusion