



Connecting Our Community

# 6th PATIENT CONGRESS 2017

## Congress Agenda

### Thursday, 6 April

#### A<sup>1</sup> Global Patient Congress Arrival

6:30 pm - 8:30 pm

#### Welcome Reception and Dinner

Meet & Greet between patient, research and medical communities

1st Floor Restaurant

### Friday, 7 April

7:00 am - 8:45 am

#### Breakfast

1st Floor Restaurant

9:00 am - 9:10 am

#### A<sup>1</sup> Global Patient Congress Opening

- Welcome

Karen Skålvoll (Emcee), Norway  
Gonny Gutierrez, Alpha-1 Global

9:10 am - 10:20 am

#### A<sup>1</sup> Research and Therapeutic Updates

- Research Conference Summary (15 mins)
- Alpha-1 Antitrypsin- Beyond Emphysema (15 mins)
- Inhaled Therapy (15 mins)
- Update on Testing for Alpha-1 (15 mins)
- Q & A time (10 mins)

Adam Wanner, USA  
Sabina Janciauskiene, Germany  
Mark Brantly, USA  
Marc Miravittles, Spain

10:20 am - 10:40 am

#### Break

10:40 am - 11:15 pm

#### A<sup>1</sup> Patient Involved Liver Studies

- Alpha-1: Testing Your Liver the Gentle Way (15 mins)
- Alpha-1 and the Modifier Genes of Liver Damage (15 mins)
- Q & A time (5 mins)

Pavel Strnad, Germany  
Marion Bouche-careilh, France

11:15 pm - 12:00 pm

#### A<sup>1</sup> Research & Medical Global Collaboration

- Dublin Forum Summary and Panel Discussion
- Global Collaboration - Next Steps:
  - Global Guidelines for Alpha-1
  - Global Patient Registries Collaboration

Gonny Gutierrez, Alpha-1 Global

12:00 pm - 12:30 pm

#### A<sup>1</sup> Strategies to Overcome Common Hurdles of Patient Access to Augmentation Therapy

- Panel Discussion

Sandra Nestler-Parr, UK

12:30 pm - 2:00 pm

#### Lunch

1st Floor Restaurant

### Friday, 7 April (Continued)

2:00 pm - 2:30 pm

#### A<sup>1</sup> Global Patient Community

- Introduction of Global Steering Committee
- Other Introductions

Karen Skålvoll (Emcee), Norway

2:30 pm - 3:20 pm

#### A<sup>1</sup> Advocacy- A Concerted Effort

- Public Policy Advancement
- Clinical Practice Advancement
- Q & A time

Sebastian Rohde, Belgium  
Robert Stockley, UK

3:20 pm - 3:45 pm

#### Break

3:45 pm - 4:10 pm

#### A<sup>1</sup> Related Conditions & Transplantation

- Skin Conditions and Other A1 Related Conditions
- Q & A time
- Organ Transplantation: Lung & Liver Overview
- Panel Discussion

Speaker TBD

4:10 pm - 5:00 pm

#### Dinner

Speaker TBD  
Karen Erickson (Moderator), USA

6:30 pm - 9:00 pm

#### Dinner

### Saturday, 8 April

7:00 am - 8:45 am

#### Breakfast

9:00 am - 10:00 am

#### A<sup>1</sup> Health Management

- Importance of Exercise
- APPs for Alphas- Using Technology to Manage your Health
- Proactive Patient-Physician Communication: Why and How

José Jardim, Brasil  
Kevin Diaz, USA  
Henry Moehring & Robert Sandhaus

10:00 hrs - 10:30 hrs

#### A<sup>1</sup> Organisations

- Effective Patient Organisations: Establishing a Strong Voice

Frank Willersinn, Belgium

10:30 pm - 10:50 am

#### Break

10:50 am - 12:00 pm

#### A<sup>1</sup> Global Commitment

- Steering Committee Panel: Ask Your Peers
- Alpha-1 Global Action Items Presentation 2017-2019
- Alpha-1 Foundation Commitment and Congress Closing

Karen Skålvoll (Emcee), Norway  
Alpha-1 Global  
Henry Moehring, USA

12:00 pm - 1:30 pm

#### Lunch

1st Floor Restaurant