

London 2010



*5th European
Alpha1 Congress*

Dear members and guests,

The Fifth Alfa Europe Federation Congress coincides with new directions in the provision of health care in Europe. There are natural tensions between the growing appreciation of patient rights, an ageing population profile and innovative medical treatments which are often very expensive. On the positive side political leaders have stated that health and healthcare are central to the development of a just and equal community of nations. Now is the time to add the voice of the Alpha patients to those visionaries looking forward to a healthier world.

The 27 member states of Europe have signed up to commit themselves to create a National Plan for Rare Diseases in each country. Three elements that should be central in these strategies are continuity and research, timely diagnosis and, most importantly, patient care with equitable and timely access to treatment. Over the coming years the Federation and the associated rare disease organisations can assist our member associations to make positive contributions to the plans being developed in their own countries.

London has two thousand years of constantly changing history. Let us continue that tradition of change by making improvements in the lives of people affected by Alpha1 Antitrypsin Deficiency.

The Board of Alpha1 Awareness UK are pleased to welcome the Alfa Europe Federation members to the United Kingdom. We hope that your stay will be informative, relaxed and pleasurable with enough time to see some of the sights of our capital city.

Alan Heywood-Jones
President
Alfa Europe Federation

Nursery



Do you require the services of a child-minder on Saturday 10th July?
Trained staff from an agency will be on hand to take care of your little ones during the presentations.



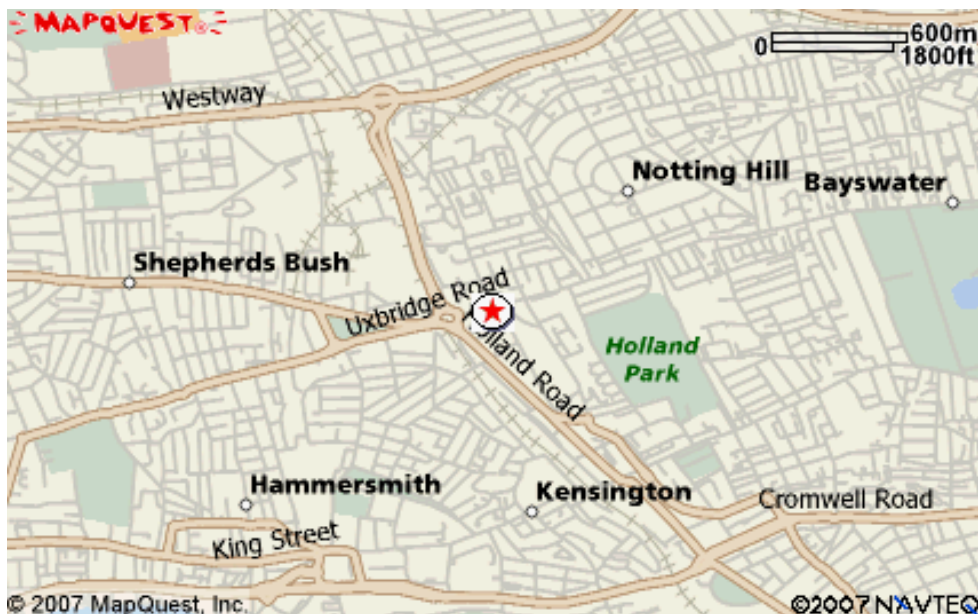
Hilton London Kensington hotel

Hilton London Kensington hotel
179-199 Holland Park Avenue
London, United Kingdom W11 4UL

Tel: 44-207-603-3355 Fax: 44-207-602-9397

www1.hilton.com/en_US/hi/hotel/LHRHITW-Hilton-London-Kensington-hotel/index.do

Travel Information



Directions and access to Hilton London Kensington

By Tube:

We are 7 minutes walk from Holland Park tube station and 6 minutes from Shepherd's Bush over ground and tube station, both giving easy access to the city. We are a short tube journey from Paddington Stations for connections to the West of England and 6 stops to Oxford Circus.

By Car:

From the A40 (Westway) take the A3220 exit to the Shepherd's Bush roundabout and turn left onto Holland Park Avenue. The hotel is on the right. From the M4 take the A3220 north to the Shepherd's Bush roundabout then turn right onto Holland Park Avenue.

London Heathrow Airport

Heathrow Express train, terminates at Paddington Station

Distance: 21 km

Time: 45 min

Taxi: £ 35

London Gatwick Airport

Gatwick Express terminates at Victoria Station

Distance: 42 km

Time: 90 min

Taxi: £ 85

Paddington (train station)

Distance: 2 km

Time: 5 min

Taxi: £ 5

Earl's Court and Olympia Exhibition Centres

Distance: 2 km

Time: 5 min

Taxi: £ 5

Holland Park (tube)

Distance: 0,8 km

Time: Walk of 7 min

Please Note: The map and directions are informational only. Please verify specific routes. The map and directions shown are provided as a guide for your convenience.

Important information for members of Alpha1 Awareness UK

For assistance towards travel expenses and second night hotel costs please email „congress@alpha1awareness.org.uk“.

Friday

15:00 - 15:30

15:30 - 15:35

15:35 - 15:40

15:40 - 15:45

15:45 - 16:00

16:00 - 16:10

16:10 - 16:20

16:20 - 16:30

16:30 - 16:35

Final registration
date

June 10, 2010

09.07. 2010

Annual General Meeting

Welcome Coffee

Item 1 Welcoming address and determination of voting rights

Item 2 Election of the meeting chairman by acclamation

Item 3 Determination of a quorum

Item 4 President's annual report

Item 5 Vice-president's report

Item 6 Treasurer's annual report

Item 7 Discussion of reports

Item 8 Formal approval and exoneration of the Executive Committee's actions

The Meeting will be held in English.

The Alfa Europe Federation meeting is a closed event and can only be attended by 2 congress delegates with official voting rights from each European country.

Only official members of the Alfa Europe Federation are entitled to vote. Guests and observers are warmly welcome.

All conference and accommodation costs will be covered by the European Alpha1 Foundation for delegates and their immediate family members staying in a double room (spouse, parents e.g.). This does not include drinks from the mini-bar, telephone charges or consumption outside of the event.

Hilton London Kensington

Alfa Europe Federation

Item 9 Election of the board

Election of the president

Election of the vice president

Election of the treasurer

Election of the vice treasurer

Election of the secretary

Item 10 Election of the cash auditors 2011

Item 11 Report from the Foundation

Tee/Coffee Break

Round table discussion

Item 12 Work schedule for the coming year

Dinner

The Meeting will be held in English.

Important Information

We kindly request every new member group (association) to send proof of identity to Juergen Schulz, as well as proof that they are board members of their organisation. Board members of the associations are able to appoint members of their own group with power of attorney (power of proxy). A member may act as holder of a mandate for up to two other members.

Alfa Europe Federation

Telephone: +49 (0)2365-698260

email: alfa-eurofed@t-online.de

Stockumer Str. 30

D - 59354 Werne

London

16:35 - 16:45

16:45 - 16:50

16:50 - 17:00

17:00 - 18:00

18:00 - 19:00

19:30

All online registration forms can be found at

www.alpha1-europe.eu

Saturday

10.07. 2010

Scientific Programme

09:30 - 09:40

Conference Opening & Introduction

09:40 - 10:00

Prof. Sabina Janciauskiene
MHH Hannover, Germany
What is Alpha1-antitrypsin-deficiency?

10:10 - 10:30

Dr Nedim Dino Hadzic
King's College Hospital, London
Liver Disease of children

10:40 - 11:00

Tee/Coffee Break

11:00 - 11:20

Prof. David Lomas, PhD ScD FRCP FMedSci
University of Cambridge
Developing a cure for antitrypsin

11:30 – 12:00

Dr Heinz Steveling
Ruhrlandklinik Essen, Germany
20 Years of Replacement Therapy

12:00 - 14:00

Lunch

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London

Scientific Programme

Melissa Hillier

Genetic Alliance UK

Improving access to healthcare for families with rare genetic conditions

14:00 - 14:20

John W. Walsh

Alpha-1 Foundation, USA

Patient Empowerment

14:30 - 14:50

UK Patient

Alpha1 Awareness UK

Treatment in the United Kingdom

15:00 - 15:10

Tee/Coffee Break

15:15 - 16:00

For European members and guests

City Tour

17:00 - 18:30

Dinner

19:30

The event will be held in English



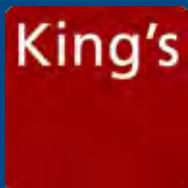
**Prof. Sabina Janciauskiene,
MHH Hannover, Germany**

Sabina Janciauskiene has obtained doctor degrees in Pharmacy, Biology, Immunology and Experimental medicine. For 20 years the overall objective of her research has been to investigate the mechanisms that control inflammation, with particular emphasis on the multiple roles of serine protease inhibitors (serpins) in Alzheimer's disease and chronic obstructive pulmonary disease. As an acknowledgement of her research achievements, she received the European CB Laurell Award 2005 for new insights into Alpha1-antitrypsin deficiency.



**Dr Nedim Dino Hadzic
King's College Hospital, London**

Nedim Dino Hadzic is a Consultant/Honorary Senior Lecturer and Honorary Reader in Paediatric Hepatology in one of the world busiest paediatric hepatology units. His special interest include primary immunodeficiencies, bone marrow related hepatic complications, autoimmune liver disease and alpha1-antitrypsin deficiency. Dr Hadzic is a leading world authority on pediatric liver disease in immunodeficiency, alpha1-antitrypsin deficiency, metabolic disease, haematopoietic stem cell transplant complications, autoimmune liver disease and liver transplantation in children.



**Prof. David Lomas, PhD ScD FRCP FMedSci,
University of Cambridge**

David Lomas qualified from the University of Nottingham and then worked as a junior hospital doctor in General and Respiratory Medicine. He moved to Cambridge as an MRC Training Fellow to undertake his PhD and then secured a second fellowship as an MRC Clinician Scientist. In 1994 he was appointed as University Lecturer at the University of Cambridge and in 1998 was appointed to the Professorship of Respiratory Biology. He has been an Honorary Consultant Respiratory Physician at Addenbrooke's and Papworth Hospitals since 1994 and has a particular interest in AATD, the serpinopathies and the genetic basis of COPD.



Dr Heinz Steveling
Ruhrlandklinik Essen, Germany

Heinz Steveling is Assistant medical Director of the department Pulmonology - University hospital Ruhrlandklinik in Essen. For 20 years he has intensively dealt with the ambulant and stationary care of alpha1 patients. A patient meeting is held once a year under his leadership in the accommodations of the Ruhrlandklinik where alpha1 patients can get information about their disease during the meeting. In addition he is responsible for the further training of medical doctors in order to make AATD more familiar.



Melissa Hillier
Genetic Alliance UK

Melissa Hillier is the Assistant Director at the Genetic Alliance UK - formerly genetic interest group - an alliance of charities and support groups for all people affected by genetic disorders. She has worked at GIG for over five years, initially in the role of Communications Manager, and has developed a network of contacts across the UK and has an in-depth understanding of the impact of genetic conditions on individuals and families, the complex decisions that they are often faced with and the difficulties that they experience in accessing treatments, services and products. Melissa Hillier has an MA in Public Communications and Public Relations.



John W. Walsh
Alpha-1 Foundation, USA

John W. Walsh is the co-founder, President and CEO of the Alpha-1 Foundation in Miami, Florida. Under his leadership, the organization has become internationally recognized and has invested more than \$35 million to support Alpha-1 research and research-related projects, which includes funding grant awards to more than 70 academic institutions in North America and Europe. He is also co-founder and President of AlphaNet, Inc. a not-for-profit disease management services company providing comprehensive care exclusively for individuals with Alpha-1 Antitrypsin Deficiency.



Alfa Europe Federation European Alpha1 Foundation

Dürener Straße 270
D-50935 Köln
Germany

Telephone

+49 (0) 221-964380-0

Fax

+49 (0) 221-96438020

london@alpha1-europe.eu

info@alpha1-europe.eu

www.alpha1-europe.eu