

Berlin
2006

alpha1

*Dorint Novotel „Am Tiergarten“
Straße des 17. Juni 106 - 108
10623 Berlin
Telephone: 0049-30-6 00 35-0*



Alpha1 Germany - Charitable Association

Europe

alpha1

**ALPHA1
INFODAY
2006**

C14

13th May 2006

Annual General Meeting 2006

Friday, 12.05. 2006

6:00 p.m. to 7:00 p.m.

Dorint Novotel „Am Tiergarten“

Straße des 17. Juni 106 - 108

10623 Berlin

Telephone: 0049 - 30 - 6 00 35 - 0

The Annual General Meeting is a closed event and can only be attended by members of the Alpha1 Germany association who have voting rights.

Family members, members of Alpha1 Austria, Alpha1 Switzerland and Alfa Europe, as well as doctors holding presentations are warmly welcome to attend as guests. The event will be held in German.

Note - important additional information only for members of Alpha1 Deutschland !

For car pools with 3 or more people or groups of 6 or more travelling by rail we will be granting our members a contribution of 10.00 Euros per 100 km (calculated as an average).

30.00 Euros for a distance of 300 km in total

60.00 Euros for a distance of 600 km in total

90.00 Euros for a distance of 900 km in total

120.00 Euros for more than 1200 km

All conference and overnight costs will be covered by Alpha1 Germany for members and their immediate family members in a double room (spouse, parents, children aged up to 16). This does not include drinks from the mini-bar and consumption outside of the event.

Agenda

- Item 1 Welcoming address and establishment of quorum
- Item 2 Election of the meeting chairman by acclamation
- Item 3 Chairman's Annual Report
- Item 4 Deputy Vice-Chairman's Annual Report
- Item 5 Reports from the Advisory Boards
- Item 6 Treasurer's Report
- Item 7 Auditor's Report
- Item 9 Discussion of Reports
- Item 8 Formal approval of the Executive Committee's actions
- Item 9 A look ahead at the new year for the association
- Item 10 Any other business

Additional requests are to be submitted to the Executive Committee 14 days before the event in accordance with the articles of association.

Binding registration deadline 31.03. 2006

Alpha1 Deutschland e.V.
Telephone: 0049-221-500 75 35
Fax: 0049-180 - 506033407418
Wiener Weg 4,
50858 Köln

Your contact partner is Elisabeth Takahashi

All online registration forms can be found at
www.alpha1-deutschland.de

Alpha1 Infoday

Saturday, 13.05. 2006

09:00 a.m. to 04:00 p.m.

Dorint Novotel „Am Tiergarten“

Straße des 17. Juni 106 - 108

10623 Berlin

Telephone: 0049 - 30 - 6 00 35 - 0

The Alpha1 Infoday is a joint event organized by Alpha1 Germany and Alfa Europe and can be attended by anyone who is affected by Alpha1-Antitrypsin Deficiency together with their families and supervising doctors. We will also be supported by our cluster partners Austria and Switzerland.

Please send us your binding registration by **31.03. 2006**

We kindly ask non-members to register by telephone with our member service who will then provide you with the registration documents. This also applies to doctors that are not holding a presentation.

Have you forgotten to register or do you have some questions about the event? We will be happy to assist you.

We kindly ask European guests and doctors to contact Elisabeth Takahashi on telephone number 0049 - 221 - 5007535

All online registration forms can be found at www.alpha1-deutschland.de

Programm



Prof. Dr. Claus Vogelmeier

Univ. Hospital of Gießen a. Marburg

PD. Dr. Dr. Robert Bals

Univ. Hospital of Gießen a. Marburg

Dr. Andreas Wilke, OA

Hosp. for Pulmonary Diseases, Berlin

Dr. Klaus Kenn, Chefarzt

Berchtesgadener Land Hospital

Dr. Karin Schmid-Scherzer

Wilhelminen Hospital Vienna

Dr. Otto Brändli, Chefarzt

Höhenklinik Wald, Zurich

Dr. Thomas Köhnlein

University Hospital Hannover



Prof. Dr. Klaus-Peter Zimmer

University Hospital Münster

Prof. Dr. Klaus Pittschieler

Central Hospital Bolzano (Italy)

Dr. Rüdiger Kardorff, OA

Paediatric Hospital Wesel

PD Dr. Jürgen v. Schönfeld

Marien-Hosp. Bergisch-Gladbach

German Alpha1 Registry

Laboratory and AlphaKit

Alpha1-Centers

Characteristics of
Alpha1 Reha

Austrian Alpha1
Community

Alpha1 Community
Szene

AAT-Deficiency, Clinical
Aspects a. Management

Neonatal Screening

Data and Facts of
Neonatal Screening

Child Registry and
Alpha1 Child Center

AAT -Deficiency in Adults
Alpha1 Doc-Hotline



Larry Warren

Pascale Vlahovic



Walter Berger

Elisabeth Takahashi

President Alfa Europe

Alpha1 Schweiz

Alpha1 Österreich

Alpha1 Deutschland



Prof. Dr. Claus Vogelmeier, Univ. Hosp. of Gießen and Marburg

Claus Vogelmeier is Professor of Internal Medicine and Director of the Internal Medicine Hospital specialising in pulmonology. After his junior physician's training, he worked for two years at the Pulmonary Branch of the National Institute of Health in Bethesda, USA. Here, he studied antiprotease of the human lung, which is significantly linked to AAT. Claus Vogelmeier is an internist, pulmonologist, cardiologist and allergologist. His clinical and scientific field of specialisation is the diagnostics and treatment of obstructive lung diseases, which also include emphysema caused by AAT Deficiency.



PD Dr. med. Dr. rer. nat. Robert Bals, University Hospital of Gießen and Marburg

Robert Bals is a lecturer at the Hospital for Internal Medicine specialising in pulmonology at the University of Marburg. During his training as an internist and pulmonologist he worked on the principles of diseases of the lung. He studied medicine and biology in Munich and obtained a doctorate in both subjects. He obtained his basic scientific grounding during his biology studies and a placement in the USA. AAT- Deficiency, chronic obstructive lung diseases and the principles of congenital immune mechanisms of the lung count among his areas of interest.



Dr. Andreas Wilke, Consultant, Berlin-Buch Specialist Hospital for Pulmonary Diseases

Andreas Wilke is as a Consultant at the Department for Internal Medicine at the Berlin-Buch Specialist Hospital for Pulmonary Diseases and Thorax Surgery (FLT). When the regional "Alpha1-Center" was established in Germany in 2003, the FLT numbered among its "founder members". The treatment and care of patients with AAT Deficiency has a similarly long tradition at the FLT in Berlin-Buch. Patients from all over the former GDR were diagnosed and treated there as far back as 1987.



Dr. Klaus Kenn, Medical Director of the Berchtesgadener Land Hospital

Klaus Kenn is Medical Director of the Pulmonology Department After his studies in Human Medicine at the University of Cologne, he completed his training to become a doctor of internal medicine after 3 years of working in Friedrichshafen. This was followed by further training in pulmonary and bronchial medicine in Davos. Additionally, he obtained further qualifications in allergology and sports medicine. In addition to his specialist research in "Chronic Bronchial Asthma" and its differential diagnosis which he commenced in Davos.



Continuation Dr. Kenn

Klaus Kenn and his team have for many years been involved in training therapy for advanced pulmonary diseases, in particular with patients suffering from AAT-Deficiency emphysema. This includes both the intensive preparation and aftercare for patients undergoing lung transplants. Some 100 patients with AAT-Deficient have already been treated at this clinic and as a result all members of staff have a sound knowledge of this clinical condition. Since mid-2004, Klaus Kenn has been on hand to answer questions from our members on the Alpha-1 hotline.



Dr. Karin Schmid-Scherzer, Wilhelminen Hospital Vienna

Karin Schmid-Scherzer is a pulmonologist and was able to gain her first experience in the area of "AAT- Deficiency" during her training under Professor Kummer. After Professor Kummer's retirement, she took over the supervision of Alpha1 patients and in collaboration with established colleagues created an extensive registry of Austrian Lung Alphas within 2 years. An Alpha1-Center in Austria has also been recently set up. The II Medical Department under the direction of Professor Kneußl is one of the founder members.



Dr. Otto Brändli, Medical Director and Head of the Pulmonology Department of the Höhenklinik Wald Zurich

Otto Brändli is a Consultant for Internal Medicine and Pulmonology as well as for Physical Medicine and Rehabilitation. Parts of his studies were completed at the Universities of Vienna and Montpellier. He was Chief Resident of the Chest Service at the Bellevue Hospital in New York and later a Consultant at the Department for Respiratory Diseases at the Basel University Hospital. Mr. Brändli is President of the Lung League of the Canton of Zurich and is involved in the Swiss Environmental Study SAPALDIA as local project leader.



Dr. Thomas Köhnlein, Pulmonologist, University Hospital Hannover

While studies into screening procedures for identifying AAT-Deficiency have been running since 1996, the diffusion of firm medical knowledge regarding this disease has in recent years come into the forefront. Target groups have always been both doctors and patients. Numerous survey articles in German and international journals accompanied an overview of the disease in the form of the book "Alpha1-Antitrypsin Deficiency, Clinical Aspects and Management".



Prof. Dr. Klaus Zimmer, University Hospital Münster

Klaus-Peter Zimmer is Professor of Paediatrics and a Consultant at the Hospital for Paediatric and Adolescent Medicine, specialising in Children's Gastroenterology at the Westfälischen Wilhelms-Universität Münster. He studied Human Medicine at the University of Heidelberg and after one year as an assistant at the Institute for Pathology at the University of Hamburg, he began his training to become a doctor of paediatric and adolescent medicine at the Heidelberg University Paediatric Hospital. As part of a grant from the German Research Community, he researched molecular and biological cell problems in protein transport at the European Molecular Biology Laboratory in Heidelberg and at the

Medical School of Yale University. He completed his training to become a consultant for paediatric and adolescent medicine at the Hospital for Paediatric and Adolescent Medicine at the Westfälischen Wilhelms-Universität in Münster. There he built up a treatment centre for children and young people with gastroenterological and hepatological diseases. Professor Zimmer also completed his training as a neonatologist and paediatric gastroenterologist. Study placements led him to the Hospital for Sick Children in Toronto and London. He is Chairman of the Society for Paediatric Gastroenterology and Nutrition (GPGE). Specialist areas of his clinical and scientific work include diseases of the gastrointestinal tract and the liver which are caused by a defect in protein transport. Several of his research projects have been funded by the German Research Community. His scientific studies have been honoured with awards including the Paul-Caspar-Tyrell Prize and the Adalbert-Czerny Prize.



Prof. Dr. Klaus Pittschieler, University Hospital Bolzano

1977: Training to become a Consultant for Children and Young People's Medicine in Verona, followed by clinical training in the field of paediatric gastroenterology at several European and American centres and a two year basic research placement at the Research Centre for Paediatric Gastroenterology of the University of New York in Buffalo specialising in liver cell pathology. Qualifications: Certified in Paediatric Gastroenterology in Buffalo 1987. Klaus Pittschieler is a member of several international research groups. Since 1996 he has been Director of the Department for Paediatric and Adolescent Medicine at the Central Hospital of Bolzano and the University Hospital (South

Tyrol, Italy). Klaus Pittschieler lectures as a professor at the Paediatric Hospital of the University of Innsbruck and is also in charge of the Paediatric Gastroenterology/Hepatology Doctor Training Programme at the University of Verona. In 1986, he established a neonatal screening system for Alpha1-Antitrypsin Deficiency using phenotyping. In almost 20 years of screening, nearly 100,000 new born babies have been tested as a result in the "Autonomous Province of Bolzano" and their development has been followed in a special out-patients department. A wealth of new data, in particular regarding heterozygotes and unusual phenotypes, has been gathered and published to date. Numerous presentations subsequently followed, including a presentation at the Annual General Meeting of the American Alpha1 Foundation 2003.



Dr. Rüdiger Kardorff, Consultant, Clinic for Paediatric and Adolescent Medicine at the Marien-Hospital Wesel

Rüdiger Kardorff is a Consultant at the Clinic for Paediatric and Adolescent Medicine at the Marien Hospital Wesel (Lower Rhine). After studying medicine at the Hannover Medical School (MHH), Dr. Kardorff began his training there as a paediatrician. He worked for the MHH for over ten years, lastly in the position of Consultant. In addition to his scientific specialisation in researching tropical infections, he also focussed in Hannover on liver diseases and liver transplants in children, in particular with metabolic diseases of the liver such as Alpha1-Antitrypsin Deficiency.

Dr Kardorff is certified as a Paediatric Gastroenterologist of the “Society for Paediatric Gastroenterology and Nutrition (GPGE)” and is a recognised specialist in ultrasound diagnosis for children, in particular focussing on diseases of the liver and other abdominal organs. For some time now he has been available through Alpha 1 Germany to give advice with regard to the paediatric aspects of A1AT Deficiency, providing a telephone advice for affected families every Monday. Rüdiger Kardorff is responsible for the German-wide Alpha1 Children’s Registry.



PD. Dr. Jürgen von Schönfeld, Medical Director, Gastroenterology, Hepatology, Head of the Internal Medicine Department of the Marien Hospitalin Bergisch Gladbach

Jürgen von Schönfeld is an internist specialising in gastroenterology and hepatology. For the last 4 years, he has been Head of the Internal Medicine Department at the Marien Hospital in Bergisch Gladbach, which is an academic training hospital of the University of Cologne. After studying in Bonn, Berlin and Cologne, he then worked for 1 year at the Pathological Institute of the University of Cologne before starting his internal medicine training at the University Hospital Essen. Early on he concentrated clinically and scientifically on the specialist field of gastroenterology and hepatology. In particular he specialised in the areas

of endoscopy, sonography and hepatology. This resulted in close collaboration with liver transplant surgeons at the University of Essen and cooperation with pulmonologists at the Haidhausen Lung Hospital. Since 1994, Jürgen von Schönfeld has been an internist and since 1996 a gastroenterologist. After several years as a consultant and gastroenterologist in charge at a large hospital in Duisburg, he was appointed as Medical Director at Bergisch Gladbach in 2000. In addition to his work attending to in-patients, he is also authorised by the Health Insurance Association to treat out-patients. This provides excellent opportunities for integrated out-patient/in-patient diagnosis and therapy. Scientifically he has dealt with various subjects from the fields of gastroenterology and hepatology and has published works on these areas. He focussed on functional disturbances and metabolic disturbances which also included Alpha1-Antitrypsin Deficiency.



ALFA EUROPE
EUROPEAN FEDERATION FOR ALPHA1 ANTITRYPSIN DEFICIENCY

**Second Alfa Europe
Alliance Meeting**

Sunday 14th May 2006
9:00 a.m. to 1:00 p.m.

Dorint Novotel „Am Tiergarten“
Straße des 17. Juni 106 - 108
10623 Berlin
Telephone: 0049 - 30 - 6 00 35 - 0

**The Alfa Europe foundation meeting is a closed event and can only be attended by 2 Congress Delegates with official voting rights from each European country. Guests and Observers are warmly welcome.
The event will be held in English.**

Only for Delegates:

All conference and overnight costs will be covered by Alpha1 Germany for members and their immediate family members in a double room (spouse, parents, children aged up to 16). This does not include drinks from the mini-bar and consumption outside of the event.

Agenda

- 1. Election of the meeting chairman by acclamation**
- 2. Establishment of membership subscription regulations**
- 3. Distribution and completion of membership declarations**
- 4. Formation of an electoral committee**
- 5. Appointment of an election officer and a helper**
- 6. Secret election of the Executive Committee by the founder members of the alliance**
- 7. Election of the Advisory Committee**
- 8. Certification of the signatures by a notary**

The Executive Committee, which is entitled to act as representatives, was further authorised by unanimous decision to make any necessary amendments or alterations to the draft articles of association should the Registration Office or Tax Authorities raise concerns regarding the registration or recognition of the alliance's status as a charitable organisation.

It was clarified that this decision does not relate to the provisions of any other articles of association.



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