



Observational trial

Patients included: 446

High data quality is a hallmark of the register!

Complete cases make a lot of fun and give satisfaction

Observational trial – News I

New SOP Biosamples- labeling in the database: read about the “Collection number”!
Available on the chILD EU database welcome-page. Also see updated Lab manual.

Observational trial - News II

Always IMMEDIATELY decide on the observational type and generate “more visits”. This will activate a single reminder for upcoming visits.

Upcoming activities

1. chILD EU meeting in Ankara

Please find attached the Agenda of the **next chILD meeting in Ankara**, 15th to 16th January 2016.

For hotel reservation and airport transfer please contact:

Valör Congress Organizations

Phone: +90 312 491 9999

Email: valor@valor.com.tr

Address: Turan Gunes Bulvari 571. Cadde 576. Sokak No: 28 Oran Cankaya,
Ankara / Turkey



Observational trial



European Management
Platform for Childhood
Interstitial Lung Diseases



Hacettepe University
Faculty of Medicine
Department of Pediatrics
Department of Pediatric Chest Diseases



Interstitial Lung Disease in Children

sharing knowledge and experience across Europe

January 15-16, 2016 Hacettepe University Culture Center Hall R - ANKARA

DAY 1 Friday 15 January, 2016

- 14.00-14.30 Registration
- 14.30-14.45 **Welcome**
- 14.45-15.30 **Business Meeting**
Meeting with all chILD EU Members
- 15.30-16.00 Coffee break
- 16.00-18.00 **chILD Cases- Clinical-Pathological-Radiological Web Based and Interactive Sessions**
Turkish Team, German Team, Italian Team
- 19.00 **Dinner**

DAY 2 Saturday 16 January, 2016

- 08.30-09.00 Registration
- 09.00-09.30 **Session 1: Discovering chILD**
Children's ILD New Classification Systems - What are the Needs for the Future
Güzin Cinel
- 09.30-10.40 **Multi-Disciplinary Approaches to Patients with a Suspected chILD**
- Clinical Clues
Deborah Snijders, Angelo Barbato
 - Lung Imaging - How to Differentiate Inflammation, Fibrosis and Cystic Lesions
Berna Ögüz
 - Histopathology of Lung Biopsy - Where are the Limits?
Diclehan Orhan
 - Genetic Testing in chILDs
Annick Clement, Ralph Epaud



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- 10.40-11.00 Coffee break
- Session 2: chILD: An Overview**
Lung Disease and Pediatric Rheumatologic Disorders
Seza Özen
- 11.30-12.00 **Immune Deficiency and Dysregulation in Diffuse Lung Disease**
Ilhan Tezcan, Nural Kiper
- 12.00-12.20 **Exacerbation in chILD Definition and Biomarkers of Pulmonary Exacerbation in chILDs**
Nicolaus Schwerk, Annick Clement
- 12.20-12.50 **Bronchiolitis Obliterans**
Steve Cunningham
- 12.50-14.00 Lunch
- Session 3: Management of chILD and Case Presentations**
Management of chILD Current and Future Approaches
Matthias Griesse
- 14.30-16.00 **chILD Cases- Clinical-Pathological-Radiological Web Based and Interactive Sessions**
UK-Team, French Team, Polish Team
- 16.00-16.15 Coffee break
- Session 4: Future chILD projects**
Update on chILD EU Register and Biobank
Matthias Griesse
- 16.30-16.45 **Discussion, New Project Suggestions**
- Closing of the Meeting**

2. Symposium and Workshop - Bronchiolitis Obliterans

“Dear Ladies and Gentlemen, Dear Colleagues,
on behalf of the Foundation *Starke Lunge* I cordially invite you to the **Symposium and Workshop - Bronchiolitis Obliterans** that will be held on the **5th + 6th of February 2016** at Schloss Johannisberg in the Rheingau, one of Germany's most beautiful wine regions. National and international experts will present state of the art diagnostics and treatment for bronchiolitis obliterans (post infectious, after lung transplantation and after stem cell transplantation) in children and adults. Our goal is to develop a consensus statement for the diagnosis and treatment of BO. We explicitly encourage young scientists to present their own work in the field of rare lung diseases and to discuss their work with our experts. Please find all relevant information for registration and booking in the pdf file attached or refer to our website <http://starkelunge.de/bo-meeting/?lang=en>

For further information please contact me directly via mail.
Sincerely Martin Rosewich”



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Invitation and greetings from the founders

Dear Ladies and Gentlemen,

We cordially invite you to our first Bronchiolitis Obliterans (BO) Symposium which will take place on 5th and 6th of February, 2016 in Schloss Johannisberg.

The goal of our foundation is to help children and their families suffering from a rare, chronic lung disease. We focus on the treatment of children and adolescents with bronchiolitis obliterans (BO) and ask you for your scientific support.

Our goal is to create an international network to exchange and publish scientific knowledge on BO as new therapies are desperately needed.

We especially invite young scientists to present their research and welcome all poster submissions. The winning poster will be awarded a prize of 250,- Euro.

We look forward to meeting you,

Julia & Frank Fischer
Stiftung Starke Lunge
Founders

Practical Information

Main Contact/ Registration/ Questions

Dr. med. Martin Rosewich
Tel.: +49 69 - 66 98 30-24
Fax: +49 69 - 66 98 30-16
Mobil: +49 151 - 40 567 007
martin.rosewich@starkelunge.de

Venue

Schloss Johannisberg
65366 Geisenheim-Johannisberg
<http://www.schloss-johannisberg.de>

Hotels

Burg Schwarzenstein (Relais & Château)
Rosengasse 32, 65366 Geisenheim-Johannisberg,
Tel.: +49 6722 - 99 50 0
Fax: +49 6722 - 99 50 99
E-mail: info@burg-schwarzenstein.de
<http://www.burg-schwarzenstein.de/>
Single Room (Breakfast incl.) € 130,00

Kloster Johannisberg
Benediktus Hort GmbH, Badpfad 1,
65366 Geisenheim-Johannisberg
Tel: +49 6722 49 79 10
e-mail: info@kloster-johannisberg.de
<http://www.kloster-johannisberg.de/>
Single Rooms (Breakfast incl.):
Classic € 89,00 - Standard € 69,00

Friday, 05.02.2016

- 10:30 Reception and Welcome
- 11:00 Introduction
M. Rosewich
- 11:15 Patient Networks and Patients Needs
A. Gettys
- 11:45 Clinical Symptoms and Signs in Post-Infectious BO (PIBO)
S. Cunningham
- 12:15 - Lunch Break -
- 13:10 Development of BOS after Lung Transplantation - Current Pathophysiological Concepts
N. Schwerk
- 13:35 Bronchiolitis Obliterans after SCT - Clinical Signs and Treatment Options
A. Jarisch
- 14:00 Categorization and PIBO Cases in the chILD - Network - Relation to other ILD
M. Griese
- 14:25 BO Post Infection & Post Transplantation Discussing the Differences in diagnosis and management
M. Griese, N. Schwerk, S. Cunningham,
- 15:00 - Coffee Break -
- 15:25 Lung Function, LCI and beyond What to Expect in Bronchiolitis Obliterans
P. Latzin
- 15:50 Radiological Findings in chILD
A. Calder
- 16:15 Radiological Findings in BO
S. Martin

- 16:40 Treatment Options of BOS after Lung Transplantation
C. Neurohr
- 17:05 The psychological impact of a chronic (lung) disease on parents and children
L. Goldbeck
- 17:40 Summary and Discussion
S. Zielen
- 18:30 Guided Tour through the Wine Cellar
- 20:00 - Diner -

Saturday, 06.02.2016

- 08:30 Therapeutic Options and Potential Future Therapies
A. Casey
- 09:15 Classification, Evaluation, and Management of Bronchiolitis Obliterans in Infancy - What we have learned so far?
G. Kurland
- 10:15 - Coffee Break -
- 10:30 Working Groups
1. History and Anamnesis
(Kurland/ Schwerk)
 2. Clinical Course and Lung Function
(Griese/ Latzin)
 3. Radiological Findings
(Calder/ Martin)
 4. Biomarkers
(Schubert/ Rosewich)
- 12:30 Summary and Prospects
M. Rosewich

Registration & Booking

Registration is now open

For your registration please visit:

<http://starkelunge.de/bo-meeting/registration>

The registration fee is € 55,00, for registration by December, 20th, 2015. Late registration fee is € 65,00. This fee includes coffee breaks, lunch on Friday and the dinner on Friday evening in Burg Schwarzenstein.

(Registration is free for poster presenters and students.)

In case of any questions, please do not hesitate to contact us directly.

Accommodation

We kindly ask you to arrange your accommodation with the hotel directly. Special rates are arranged for you with Burg Schwarzenstein and Kloster Johannisberg. For your booking, please refer to the following code „Stiftung Starke Lunge“ to get the special rate.

Please check your options at:

<http://starkelunge.de/bo-meeting/accommodation>



Bronchiolitis Obliterans Symposium & Workshop 05. + 06.02.2016

Schloss Johannisberg
Geisenheim - Rheingau
Germany



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We wish you all a very merry Christmas and a happy new Year. Thank you so much for your work and support in 2015. It was a great year for the child EU database with a lot of progress. As there are still a lot of things to do we hope to go on together with our work in 2016 and hope to see you all in Ankara!