HSK
Dr. Horst Schmidt Klinik
Klinik für Kinder und Jugendliche

Invitation

Opening Ceremony
of the Center
for Rare Diseases

Wednesday, February 4th, 2015
2.00 to 6.00 p.m.
Dr. Peter Jäger Bildungszentrum
HSK, Dr. Horst Schmidt Kliniken
Wiesbaden

Agenda

2.00 to 2.45 p.m.	**Welcome speech** Dr. med. Ralf Engels, Managing Director HSK Prof. Dr. med. Markus Knuf, Director Dep. of Pediatric and Adolescent Medicine Maurizio Scarpa MD PhD, Director CRD
2.45 to 3.00 p.m.	**National action schedule for people with rare diseases** Christoph Nachtigaeller, ACHSE e.V., Allianz Chronischer Seltener Erkrankungen e.V.
3.00 to 3.15 p.m.	**EU-Engagement for people with rare diseases** Maria da Graça Carvalho, BEPA, European Commission
3.15 to 3.30 p.m.	**EU-Research – The "Brains for Brain" foundation** David Begley, Foundation "Brains for Brain"
3.30 to 3.45 p.m.	**Rare but not so rare** Helmut Hehn, Society for Sclerosis Tuberosa e.V.
3.45 to 4.00 p.m.	**Importance of networks** Carmen Kunkel, Society for Mukopolysaccharidosen e.V.
4.00 to 4.15 p.m.	**Helios-network** Prof. Dr. med. Stefan Wirth, Head of the section "pediatric and neonatology", Director of the Center for Pediatrics and Adolescent Medicine, HELIOS Klinikum Wuppertal
4.15 to 4.45 p.m.	**Patients' Performance**
4.45 to 6.00 p.m	**Exhibition "Closer than Rare", Networking and refreshments**

Opening Ceremony of the Center for Rare Diseases on February 4, 2015

The Team: Prof. Maurizio Scarpa & Dr. med. Christina Lampe

Prof. Maurizio Scarpa MD PhD , Director of the Center for Rare Diseases

State Minister Stefan Grüttner, Hessen Ministery for Social Affairs and Integration

Guests of the Opening Ceremony

Dr. med. Ralf Engels, General Manager of the HSK

Univ.-Prof. Dr. med. Markus Knuf, Director of the Clinics for Children and Adolescent Medicine

Guests of the Opening Ceremony

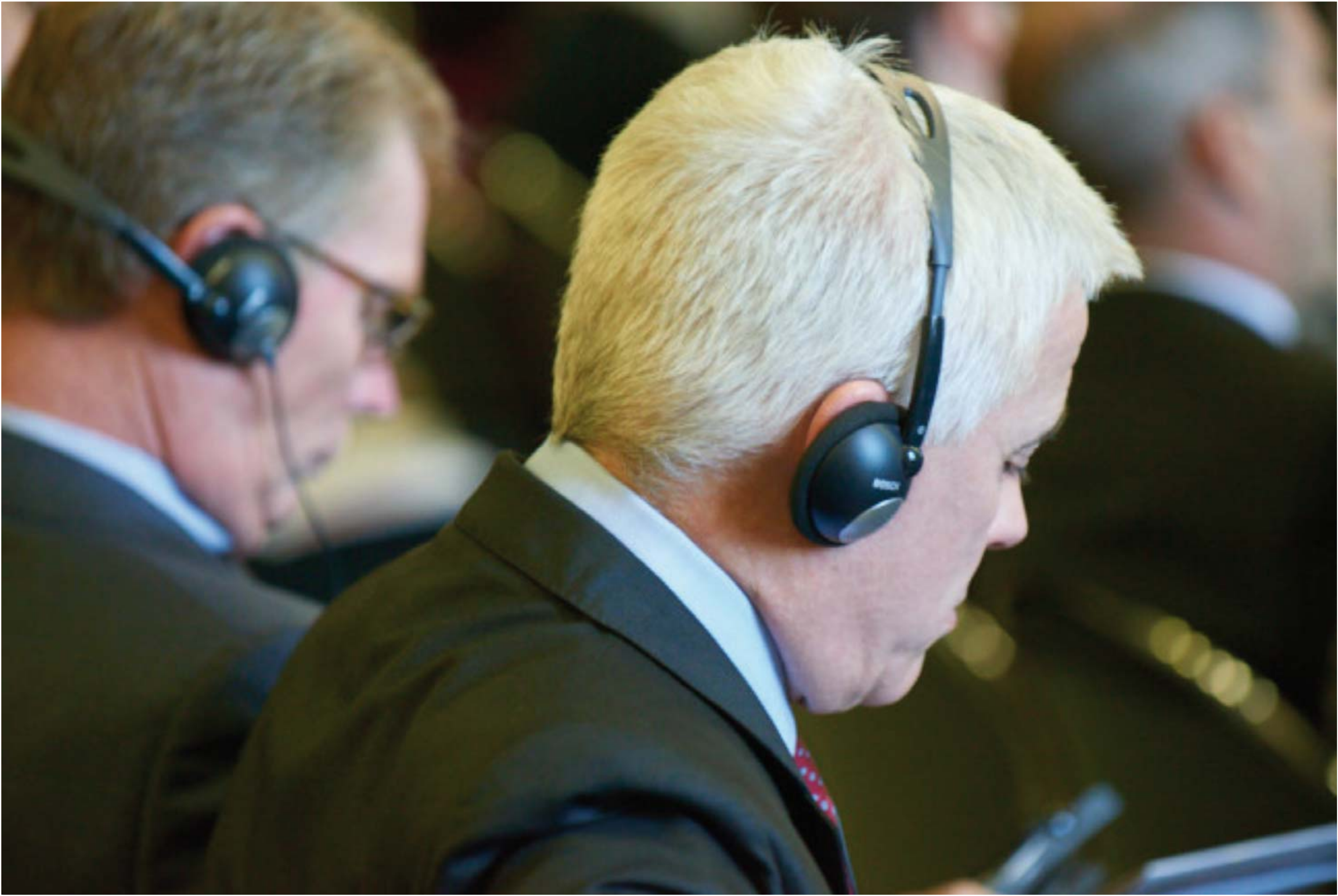
„Should you wish to travel quickly, go alone but, should you wish to travel far,
it is best to go together

Prof. Maurizio Scarpa is reading the speech of Prof. Maria Da Graça Carvalho, MEP

Christoph Nachtigäller, Honorary Chairman of the ACHSE e.V.

Gift for Christoph Nachtigäller

Simultaneous Translation German to English



International Guests: Jim Lennertz and Roberto Lore

Dr. David Begley, King‘s College London, UK, Vicepresident of the Brains For Brain Foundation

Gift for Dr. Begley

Helmut Hehn, Federal Chairman of the Tuberöse Sklerose Deutschland e.V. (TSDeV)

Carmen Kunkel, Chief Executive Officer of the Gesellschaft für Mukopolysaccharidosen e.V.

Dr. med. Christina Lampe and Carmen Kunkel

Guests of the Opening Ceremony

Prof. Dr. med. Stefan Wirth, Director of the Center of Pediatric and Adolescent Medicine,
Helios Klinikum Wuppertal

Gifts for Speakers

Annalena Schulz is Playing Violin

Annalena Schulz is Playing Violin

Annalena Schulz Made a Moving Speech




Annalena Schulz and Dr. med. Christina Lampe



Melissa Wesseler, Dancer of the Dancing School Hull, Osnabrück

Performance of the Dancers of the Dancing School Hull, Osnabrück

„ I‘M SO HAPPY“ Dancers of the Dancing School Hull Moved Guests to Dance

Prof. Maurizio Scarpa and Dancers of the Dancing School Hull, Osnabrück

Anna Marie Lampe, Speech to Open the Buffet

Photo for the Local Press „Wiesbadener Tagblatt“

Helmut Hehn with Christoph Nachtigäller

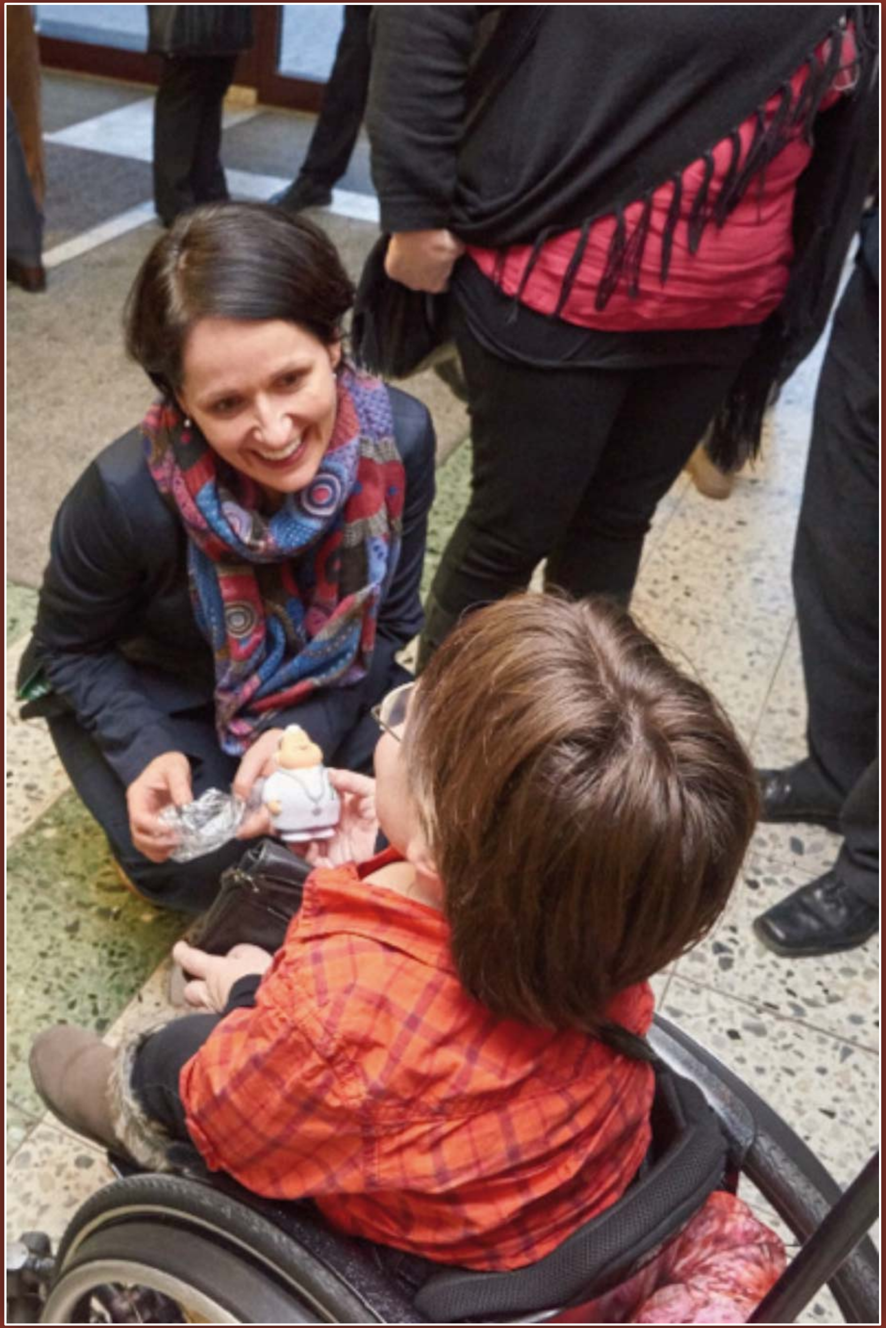
Guests with Dr. med. Katrin Schüttler and Prof. Maurizio Scarpa

Prof. Generoso Andria, University of Naples, Italy and Prof. Maurizio Scarpa

Network and Refreshments

Guests

Guests



Honorata Doba, Regional Manager Hessen Corporate Communications & Marketing, HELIOS Kliniken GmbH and Maria Prähofer

Exhibition Catalogue | February 2015

Portugal Rare
Diseases Federation

Let's make rare a capital word

'Closer'
than 'Rare'...

A Project

Partner

Exhibition Catalogue | February 2015

03
FEDRA

editorial

With the purpose of impacting the institutional leaders and the society to the problem of rare diseases, regarding particularly the patients' discrimination in accessing orphan therapeutics, Fedra organized a photo exhibition called "Closer than is Rare"

Through a collaborative partnership of renowned portuguese photographers, images of 26 patients with rare diseases were captured in black and white. This photo exhibition was already open to the portuguese public on our Parliament, in Lisbon, and also in Brussels, on the European Parliament

The FEDRA (Portugal Rare Diseases Federation) was constituted on February the 13 rd, 2008 and its part of the European project of rare diseases - EURORDIS.

Formed with the primary objective of representing the different associations for rare patients in the country, FEDRA acts primarily at a public administration level, regarding policies related to rare diseases, acquisition and reimbursement of orphan drugs, searching for implementation of a epidemiological registration data with patients with rare diseases, as well as legal representation in international organizations who share the same goals.

The Exhibition „Closer than Rare"- a Donation of Rarissimas, Portugal

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„Should you wish to travel quickly, go alone but, should you wish to travel far, it is best to go together“ – WE WANT TO TRAVEL TOGETHER WITH YOU !!!

Photos: Stark PhotoProduction, Mainaschaff

Many Thanks to all Participants and for all the Good Luck Wishes !!!!!