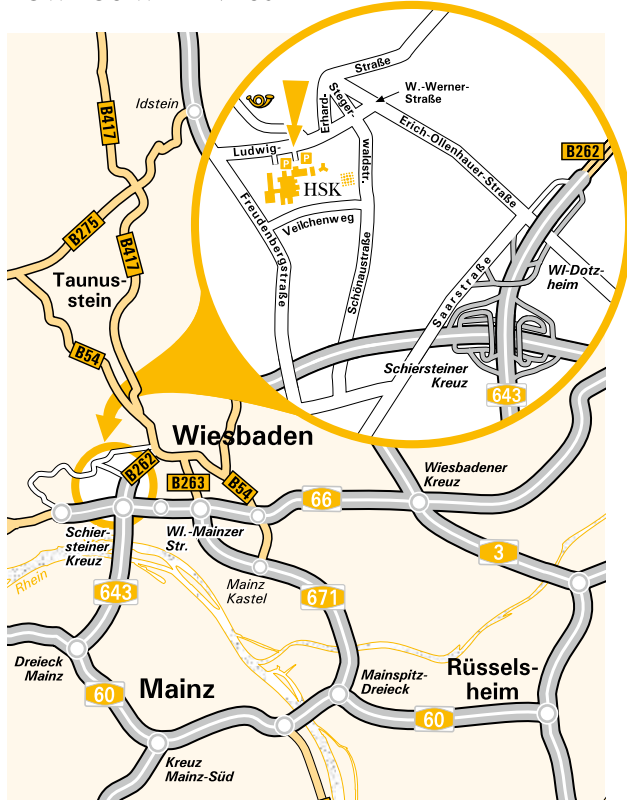


HOW YOU WILL FIND US



HSK
Dr. Horst Schmidt Klinik

HSK, Dr. Horst Schmidt Kliniken GmbH
Ludwig-Erhard-Straße 100, 65199 Wiesbaden
☎ 0611 43-9989, ☎ 0611 43-9959

Contact person:
Melanie Plewka,
Office, Center of Rare Diseases (CRD)
☎ 0611 43-2314
email: melanie.plewka@helios-kliniken.de

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

Foreword

DEAR SIR OR MADAM,

About four million people in Germany and 30 million in Europe are estimated to suffer under one of 8.000 actually known rare diseases. In their total they are so numerous that they represent a quarter of the worldwide appearing diseases. But their seldom appearance makes it a great challenge for modern medicine.

Often, the diseases are multisystemic and there are no main symptoms. Therefore a complex and interdisciplinary collaboration in diagnosis and treatment are necessary.

About one year ago, we started to bundle our experiences and established a Center for Rare Diseases at HSK, Dr. Horst Schmidt Kliniken. With the new fellow partner of the HELIOS Group we gained additional potential, due to the fact that we now belong to a German-wide network of 110 acute hospitals and rehabilitation hospitals, 49 ambulatory healthcare centers, five rehabilitation centers and 15 nursing homes.

Today we sincerely invite you to the official opening ceremony of the Center for Rare Diseases (CRD). We would like to present you our expertise and invite you to discuss with us and external experts the newest trends and challenges.



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

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**