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 Ministry for Social Affairs and Integration
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
International Guests: Jim Lennertz and Roberto Lore
Dr. David Begley, King’s College London, UK, Vicepresident of the Brains For Brain Foundation
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
Prof. Dr. med. Stefan Wirth, Director of the Center of Pediatric and Adolescent Medicine, Helios Klinikum Wuppertal
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
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 13th, 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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Passion to live dyes of red the darkness of my illness!

Paroxysmal Nocturnal Hemoglobinuria

The Exhibition „Closer than Rare“- a Donation of Rarissimas, Portugal
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– WE WANT TO TRAVEL TOGETHER WITH YOU !!!

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

Photos: Stark PhotoProduction, Mainaschaff