

Program / 18th CHARGE Conference

Friday June 21st, 2024:

- from 12.00 o'clock noon Arrival and lunch
Start of individual meetings with the CHARGE experts
- 1.30 PM **Claudia Junghans, President (Germany)**
Official welcome and information
- 2.00 PM **Lecture by Meg Hefner (USA)**
“CHARGE 101 – Overview of CHARGE / Walk a mile in my shoes”
Everything you need to know about CHARGE syndrome including a CHARGE simulation
- 4.00 PM Break
- 4.15 PM **Lecture by Dr. Kim Blake (Canada)**
„The guts of it: CHARGE syndrome and the gastrointestinal tract”
- 6.00 PM Dinner
- 7.30 PM Family introduction round, campfire bread and get together

Saturday June 22nd, 2024:

- from 7.30 AM Breakfast
- 10.00 AM **CHARGE Adult Panel**
„My life, my wishes, my aims.“
We are looking forward to listen to Elena Breitsameter, Julian Heilmann and Marcel Schmidt.
- 12.00 o'clock noon Lunch
- 2.00 PM **Lecture by Markus Wilken (Germany)**
“Treatment of feeding tube dependency in CHARGE syndrome”



PARALLEL

- 2.00 PM **Discussion group moderated by Nancy Hartshorne and Julie Maier for parents over 55 / over 60**
“What happens when we are no longer there?”
Discussion group on the topic of fears about the future, retirement plans and the ability to pass on

- 3.45 PM Coffee break
- 4.15 PM **Lecture by Dr. David Brown (USA)**
„6 things, that most people don't know about CHARGE syndrome“
The six most common things we overlook in CHARGE syndrome
- 6.00 PM Dinner
- 7.30 PM **Join-in concert by the “GroßstadtEngel”,**
singing and dancing together
Parallel: public viewing of the European Soccer Championship

Sunday June 23rd, 2024:

- from 7.30 AM Breakfast
- 9.00 AM **Lecture by Nancy Salem-Hartshorne (USA)**
“Adulging: It can be done!”
- 10.15 AM Break
- 10.30 AM **Lecture by Prof. Tim Hartshorne (USA)**
“Making sense of behavior”
Why it all makes sense
- 11.45 AM **„Deep thoughts“ Dr. David Brown (USA)**
- 12.15 PM Lunch and end of the conference

-  **Consultants with the experts from Friday to Sunday**
-  **Book table with literature on the CHARGE syndrome**

Please note:

All presentations in English will be translated **simultaneously**. Interpreters will also be available (if required) for the individual interviews with CHARGE experts. For a communication without **barriers sign language interpreters** will be on hand (German sign language).

Funded by:

Gefördert durch die
Aktion
MENSCH

Program for teenagers and adults with CHARGE - syndrome

Friday June 21st, 2024:

from 12.00 o'clock noon	Arrival and lunch
1.30 PM	<u>Claudia Junghans, President (Germany) – conference room</u> <i>Official welcome and information</i>
2.00 PM	introduction round for young people with CHARGE syndrome
4.00 PM	<u>Video workshop – Part 1</u> <i>We create short videos about CHARGE for social media</i>
6.00 PM	Dinner
7.30 PM	Family introduction round, campfire bread and get together

Saturday June 22nd, 2024:

10.00 AM	<u>CHARGE Adult Panel – conference room</u> „My life, my wishes, my aims.“
12.00 o'clock noon	Lunch
2.00 AM	<u>“Time to get up and move!” with Astrid Knipping and Christian Pawlak</u> <i>Guided hike through Oberwesel with breathing and relaxing elements from Tai Chi</i>
4.00 PM	<u>Video workshop – Part 2</u> <i>We create short videos about CHARGE for social media</i>
6.00 PM	Dinner
7.30 PM	Join-in concert by the “GroßstadtEngel”, singing and dancing together Parallel: public viewing of the European Soccer Championship

Sunday June 23rd, 2024:

9.30 AM	<u>Tai Chi with Christian Pawlak and Astrid Knipping</u> <i>Learn more about Tai Chi. Practical exercises / relaxation sessions / breathing exercises</i>
11.00 AM	<u>Video workshop – Part 3</u> <i>We create short videos about CHARGE for social media</i>
11.45 AM	<u>„Deep thoughts“ Dr. David Brown (USA) – conference room</u>
12.15 PM	Lunch and end of the conference

For a communication without **barriers sign language interpreters** will be on hand (German sign language).

There will be no interpreters for translating into different languages.

CHILD CARE:

Friday:	1.30 PM – 6.00 PM
Saturday:	9.30 AM – 6.00 PM
Sunday:	9.00 AM – 1.00 PM

The following extended items will be offered as a part of the child care:

- **Craft stations** run by a team of Gerrit Event Concept
- Outdoor **bubble station** and much more
- Secured **tree climbing** and **abseiling** on the fire stairs by the adventure guides
- **Swimming classes** for swimmers and non-swimmers on Friday and Saturday under direction of life-guards in the indoor pool of the youth hostel (advance reservation necessary)

Sufficient qualified staff will be available, supported by sign language (German sign language) competent persons.

SUPPORTING PROGRAM:

- Magic mirror photo fun for great memory photos
- CHARGE sales-booth
- Airbrush tattoos (only on Saturday from 1 PM – 6 PM)
- Tombola
- Join-in concert by “GroßstadtEngel” – singing and dancing together
- Public viewing of the European Football Championship