

3rd International CHM Patient Symposium, 14. - 16.09.2018 in Wiesbaden

Wiesbaden; far off from the city. The sun is shining, the temperature is pleasantly warm. The conference hotel is located in the middle of a forest. Electric main door openers, a light-flooded building, signposts and columns marked with tape facilitate navigation. A green indoor area and many seating and meeting facilities ensure comfort and facilitate the contact. The check-in takes awhile but still runs smoothly. Rooms are appropriate indeed.

Those affected by CHM have every reason to be optimistic. CHM gene therapy studies are being conducted worldwide. There have been operations undertaken in Germany as well. Day one starts with a lecture by Prof. Fischer from the Centre for Ophthalmology of the University Hospital Tuebingen. He presents results from the 2016 THOR study. Prof. Fischer describes the course of the operation and thus decreases diffuse fears in the audience. He describes the risk of viruses as carriers of the gene sequence as "dangerous as eating pizza". That sounds quite good. The collected study data on visual acuity, the field of vision as well as the exclusion of serious side effects give hope for soon approval. Then Jonathan Vine of NightstaRx reports on another study with the same underlying principle. The study results are just as promising. Admission is expected by the end of 2020. Excellent.

Snacks and drinks provide energy during short breaks. The main meals are rich and come in the form of buffets. Although I do not have a driving license as a CHM affected person, I do have a vice: smoking. While out standing in my own fog, I get to know and come to appreciate Randy from Tennessee; a chain smoker with a deep voice, Randy is also an extremely committed father to a CHM-affected child. After an intensive exchange about CHM and world politics - we could not miss out on Trump - the symposium continues: A chip implant for the blind, which does not allow color but indeed light perception. Charming photographer Iva Batistic portrays CHM-affected for a traveling exhibition in order to increase CHM awareness. The evening "After-Show-Party" in the basement is a great opportunity to get to know each other better. The exchange illustrates how strongly

institutional aid differs internationally. State support like in Germany does not exist everywhere; existential fears are far greater in other countries. The situation in Germany is good but there is no reason to not further improve it. Exhausted, everyone falls into bed. And once again it is confirmed that German standards for hotel beds do not correspond to a height of 6ft 1. But sleep is still good.

Day 2 starts with a look to the future. Stem cell therapy can cure, but in ten years at the earliest. Dr. Richter of the legal and community consultation RBM explains legal innovations. The next lecture is a first for me: Thomas Reichel talks about how to live happily with an eye disease. A mental journey through strategies for happiness that would have saved me a lot of anguish had I internalized them earlier. "Shoulda, coulda, woulda".

Next, is a lecture on ARGUS II, another implant. The lecture is followed by blind users describing their experiences - small steps into a more independent everyday life. The description of experiencing a sunset in a certain frame was awe-inspiring, the implant a "re-birth" for the users. Pure empathy.

The following is a lecture on a less invasive treatment by intravitreal injection, but only in 5-10 years' time. Eric Hartmann (CRF) tells us how important molecular genetic testing is. Not knowing anything about any specific disease means not being able to plan either. If no one registers, the authorities do not know about any cases. Thus, they do not realize the scope of the problem. Therefore, the message is: "Register!" Thomas Driscoll from Massachusetts explains how fundraising works in the US. In the evening, Randy and Thomas invite me to a visionary chat over cigarettes and beer. My introductory question, how well they get along one being a Democrat, the other a Republican, escalates in a discussion between the two of them. Note: Politics is never a good starter!

The final day provides information on CHM, molecular genetic testing and CRISPR / CAS. The latter remains promising but is still music of the future. The symposium is rounded off with information on tools and tips for making everyday life easier. Then comes the departure. The sun is shining. It is warm. Randy and Thomas are in a good mood again.

The symposium was totally worth it. Kudos to Pro Retina for the execution of the symposium and to Michael Längsfeld for the excellent organization.