

Germany - Alpha1 Information Day 2010, Dresden, Germany

As is the tradition, a members' meeting was held on the evening prior to Information Day. At this meeting the Alpha1 Deutschland committee members provided a review of the achievements of the past twelve months. These included a conference of group leaders, talks with health insurance fund representatives, attendance at continuing-education seminars and worked together with the Allianz for Chronic Rare Diseases. We were also invited to a meeting of the Joint Federal Committee at which representatives of health insurance funds, physicians' associations and the governments discuss and resolve health issues. Unfortunately, patient representatives (still) have no voting rights. In addition, several specialist conferences were held, such as the Round Table Conference for participants from the research, legal and political communities. Last but not least, an overview was given of the services that Alpha1 Deutschland offers its members. These include the adults and children service; advice on sports for alpha sufferers, oxygen and lung transplants; and Alpha1 Docline, which is currently staffed by five specialists, including an experienced pulmonologist for children and adults, a gastroenterologist for children and adults and a psychologist. The patients were encouraged to enter their names in the child and adult registry.

Information Day itself was well attended with almost 200 participants and as always provided a wealth of information. The meeting was opened by **Annette Widmann-Mauz**, Parliamentary State Secretary in the Federal Ministry of Health. As it does every year Alpha1 Deutschland then commemorated those who have passed away.



The book *Duck, Death and the Tulip* by Wolf Erlbruch, read by **Elias Tietz**, 6, with the help of his grandmother **Heike Beier**, describes with shocking frankness an encounter with death. "Duck feels she has been stalked by Death for some time. When Duck finally looks him straight in the eye, she is very frightened. However, Death spends some time with Duck. They go swimming together, climb trees and become friends, until Duck is taken away with dignity by Death."

The first talks were dedicated to conventional and complementary medicine. Drs. **Heinz Steveling** and **Helmut Reichardt** described what conventional medicine and natural medicine can achieve. They are not mutually exclusive; natural medicine is regarded as complementary, i.e. an adjunct to conventional medicine. Whereas conventional medicine focuses on treatment with bronchodilator spray, Prolastin augmentation therapy and the administration of steroids and antibiotics to treat infections, complementary medicine provides support with phytotherapy, hydrotherapy, nutritional therapy and exercise therapy. The scope of all these topics precluded detailed discussion, but future Information Days will of course provide an opportunity to dive into the individual approaches more closely.

Immunization has always been an important topic, although public awareness has only been raised since the swine flu epidemic. We were therefore pleased that Dr. **Thomas Köhnlein** from Hanover Medical School, agreed to hold a talk on this subject. He spoke about the development of vaccines, the efficacy of immunizations, the general vaccination plan, and additional immunizations for individuals with lung disease.

Professor **Sabina Janciauskiene** reported on new treatment methods in development, first explaining the genesis of Alpha1 antitrypsin deficiency, current treatment options and the prospects for the future, one being inhalation of AAT, which could become reality in the next few years. A somewhat more distant development would be the inhalation of a recombinant, i.e. an artificially manufactured, AAT, where bacteria, yeast or other cells are programmed to manufacture human AAT. So far it has not been possible to produce recombinant AAT in sufficient quantities. Another approach would be to develop an AAT gene therapy in which specific viruses are used as gene shuttles. Various tests suggest that this approach is feasible in principle, though a great deal of development work remains. Research into other AAT biological activities were also on the agenda. These include not only the inhibition of neutrophil elastase, but also disorders associated with AAT deficiency, including panniculitis, intestinal, pancreatic and cardiovascular diseases and diabetes.

Attorney **Matthias Herberg's** talk focused on rehabilitation and German legal specifics. He spoke about health insurers and the legal rights of patients, including bringing actions before the social courts. It is by no means always the insurers, who usually try to avoid settling a claim for financial reasons, who win.

Following this talk, Professor **Ernst Wilhelm Schmidt** presented the Chemnitz Alpha1 Center. The Center provides information and trains physicians in private practice, as well as offering the entire range of diagnostic testing and treatment including non-invasive home ventilation. The Center is also preparing to carry out lung transplantations.



Ursula Geissler from the German pension fund talked in detail about pensions for people with reduced earning capacity. Many alpha1 patients have to stop work prematurely for health reasons. That is why it's important to be aware of the legal requirements, waiting times, reduced earning capacity and the expected pension for people with permanent disability.

Professor **Helgo Magnussen** and **Timo Schulze** from GHD spoke about the option of home treatment. This new service will be offered to those patients who, due to the severity of their condition or because they develop severe cold-induced bronchospasms in winter, cannot visit their doctor on a regular basis. The weekly infusion is given by trained personnel at the patient's home, so that the patient can receive his or her augmentation therapy in winter as well. Alpha1 Deutschland has fought for years to secure this service.

Exceptionally, AAT and children wasn't discussed in Dresden, since the Alpha1 Children's Day in Munich followed in September.