

## **TREFFEN in NEW YORK**

**TREFFEN** der Vorstände unserer PH-Selbsthilfe e. V. und Herr Prof. Dr. Hoppe mit den Voständen, Ärzten und Wissenschaftlern der OHF in **NEW YORK** im Januar 2006.

Das Treffen in New York war sehr erfolgreich und verspricht eine gute Zusammenarbeit der PH-Selbsthilfe e. V. mit der Oxalosis Foundation in New York.

### **Unsere gemeinsamen Ziele:**

- die Publikation der seltenen Stoffwechselkrankheit primäre Hyperoxalurie.
- Informationsaustausch zwischen betroffenen Patienten und Angehörigen.
- Informationsaustausch, Aufklärung über Therapiemöglichkeiten und Erfahrungen im Umgang mit der Diagnose einer primären Hyperoxalurie.
- gemeinsamer Workshop: internationales Meeting und Konferenz europäischer und amerikanischer Vertreter (Wissenschaftler, Mediziner, Vorstände der jeweiligen Ländervereine bzw. Stiftungen) in London im Januar 2007.
- regelmässige überregionale Treffen zum Informationsaustausch für das gemeinsame Weiterkommen in der Forschung und der Therapie.
- gemeinsame Finanzierung und Unterstützung der Wissenschaftler und Mediziner in der PH-Forschung.

### **Rede auf dem Treffen**

Unfortunately, my English is not good enough to speak to you without notes, but I thought it important that I express my admiration and respect as directly as possible to you in your own language.

My name is Annette Rozsas. I am the second chairperson of PH-Selbsthilfe e. V. which was founded with your help and the assistance of German doctors.

We thank you for giving us the opportunity of participating in this conference and the rich program provided by the OHF. I am very impressed and extremely thankful for your work as you have already achieved much for PH sufferers and their families. For example in the fields of medicine and fundamental research, you have strengthened our hopes that scientific advances and all our efforts will lead to better and better therapies and ease the suffering associated with this illness.

I would now like to tell you how this illness has affected my little daughter.

When Jana was 10 days old, I noticed that she had extremely fine gravel in her diapers. I was very worried and consulted our pediatrician.

Jana was taking vitamin D at that time and I mentioned to the doctor that one of the side-effects stated on the product leaflet was kidney stones or gravel.

We stopped giving Jana vitamin D, hoping that this was the cause of the gravel. Unfortunately, this was not the case. Week by week, the gravel I found in Jana's diapers got bigger and bigger.

I sensed that the pediatrician was baffled and did not know what to do next and this made me very anxious and despairing. He referred us to the Olgahospital in Stuttgart to a professor, whom I now know must have been aware of the grave consequences of severe hyperoxaluria, as he told me when Jana was five months old, that we must expect the worst.

Two weeks after this frightening prognosis, Jana suffered renal colic and I asked my husband to take her to another clinic that was close by as Jana was in agony and I had no confidence in the professor as, essentially, he had given up on my child.

When we and the doctor opened Jana's diaper, we found a stone that was about half an inch long. I will never forget how, overcome by feelings of despair and helplessness, I tugged gently but firmly at the doctor's white coat and begged him to help Jana.

He saw our desperation and promised to help us - but looking into his eyes I could tell that he too did not

know what to do next.

He contacted Professor Hoppe who told him about what is now our current treatment using Bicitra, magnesium and vitamin B6.

Under Professor Hoppe's care and treatment, Jana is now feeling much better. I thank both him and you for working together to fight this condition.

Because of Jana's illness, my concern for other PH sufferers has grown, creating a need to do anything within my power and abilities to help sufferers.

We hope that if we cooperate on an international basis and exchange information we will bring about advances that will benefit all PH patients. It seems to me that we should make it one of our goals to encourage other countries to take up this challenge to ensure the best possible promotion of medical and scientific advances.

We will fly back to Germany with many new ideas and even stronger motivation, certain that there is much work to be done for PH-Selbsthilfe, a seed sown by the OHF, and the doctors who are helping us in Germany.

My sincere thanks to you all for listening to me









