Green sneaker initiative
A race against time

Nic runs as fast as the wind. Preferably in his green sneakers. He even flies. However, Nic is running a race against time. Against the absolute standstill. Against NBIA.

NBIA (**N**eurodegeneration with **B**rain **I**ron **A**ccumulation) **is a group of hereditary diseases of the central nervous system.**
All NBIA variants have a common main characteristic, namely iron deposits in both halves of the brain in the basal ganglia. The basal ganglia are a collection of core structures deep in the brain, whose functions include the control of specific movements and muscle tension as well as motor memory.

All NBIA variants lead to progressive movement disturbances. These are often accompanied by developmental delays, neuropsychiatric abnormalities and mental (cognitive) impairments. In addition, eye sight, speech and swallowing may also be impaired. Symptoms and the course of the disease are largely dependent on the respective genetically determined NBIA subtype and can also greatly vary from person to person. An effective therapy does not yet exist. **The most common NBIA variant is called PKAN.**
In 90% of patients, a classic PKAN starts before the age of 6 and many do not reach the age of 10. The atypical PKAN begins after the 2nd decade of life and develops more slowly.

Nic‘s chance is within reach.
Nine-year-old Nic from Zurich, Switzerland and around 7,000 other PKAN patients worldwide currently have a realistic chance of winning their race against time. The research team around Dr. Susan Hayflick, Dr. Penny Hogarth and Dr. Randy Woltjer from Oregon Health & Science University may have succeeded in developing a drug to treat PKAN. When they fed the compound to PKAN cells from humans, the abnormal biomarker levels changed to match the cells from healthy people.
The next step is to launch Phase 3 of the clinical trials, which involves testing the serum on human patients. The team around Dr. Susan Hayflick has succeeded in developing a drug for the treatment of PKAN that is intended to cure the diseased cells with the help of the CoA-Z serum. It has already been tested on human cells in the laboratory and shows promising results. What is missing for the final step is the first application on affected patients. Dr. Susan Hayflick's team is in close contact with the United States Food and Drug Administration (FDA), which supports this project. Generally, the regulatory authorities in Europe and around the world follow the FDA’s recommendations.

The clock is ticking.
In order to start the Phase 3 clinical trials with humans the research team needs to raise a total of two million U.S. dollars, which it will collect through its own "Spoonbill Foundation", in Portland, Oregon and its sister foundation "Lepelaar Stichting" in Rotterdam, The Netherlands.

Why is the project financed by donations? Dr. Hayflick’s team wants the medication to be available to people, who may not be able to afford health insurance, at a reasonable price and not at a price dictated by the pharmaceutical industry.

Please help us
Many people have already helped with their contributions, but the goal has not been reached yet. Please make a generous donation to the NBIA Foundation Switzerland in support of the families affected worldwide, who are confronted with a fatal disease that is so rare, that it receives little scientific attention.

People with rare diseases - especially children - also have the right to hope for positive and affordable research results.

Our Swiss donation account:
Arco Foundation
NBIA Stiftung Schweiz
Trottenstrasse 17
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