Stiftung für Menschen mit seltenen Krankheiten
Foundation for people with rare diseases

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Our Foundation for People with Rare Diseases saves human lives – Please help by supporting our activities

Rare genetic diseases are caused by defects in gene puzzle, severely affecting children as well

Dear readers

Have you ever heard of people – young men and women and even children and adolescent persons – suddenly dropped dead without an obvious cause during sport activities or little physical strain? One speaks of cardiac insufficiency or heart failure in such cases. A part of these cases of sudden death, however, is not due to “heart failure” but rather caused by the genetic defect harbored by the affected person during his or her whole life time. Such tragic effects of so-called rare diseases can be avoided. And that is exactly what we work for.

A disease affecting fewer than 5 people in 10’000 is considered to be rare. It is estimated that more than 5’000 distinct rare diseases affect 6-8% of the population. Accordingly, in Switzerland about half a million people are estimated to suffer from rare diseases, as many as from diabetes. About 80% of rare diseases are due to a genetic defect. Because rare diseases comprise many different medical conditions, the sufferings and needs of affected persons are not well known and thus have been little noticed.

The Foundation for People with Rare Diseases aims

- to inform medical doctors and the public on rare genetic diseases;
- to perform the required highly-specialized genetic testing of affected individuals;
- to ensure that the results of genetic testing are correctly interpreted and communicated to the patients and their family members by performing genetic counseling;
- to make sure that people with rare diseases get the right diagnosis which is the basis for successful treatment and targeted therapy;
- to ensure that relatives get informed on the risk of being carrier of the familial rare genetic disease and obtain the possibility to have a clarification of this risk by genetic testing;
- to extend the knowledge on the field of medical genetics by performing own research as well as by means of training and (post-)graduate education of young people and general practitioners.

Unfortunately, the costs of genetic testing are high and not or only partly paid by health insurances. For financial reasons, affected people would therefore abstain from undertaking steps to obtain genetic testing needed for the correct diagnosis, even if the clinical signs clearly indicate the presence of a rare genetic disease. People with low budget would not be able to get genetic testing. In the opinion of our foundation, everybody with a suspected rare genetic disease must have the right to have access to genetic testing. This is the reason why in many cases we have to bear the costs of genetic testing (at least the part not paid by health insurances).

Thank you very much for your open mind towards people with rare diseases and our charitable activities in this respect.

Your courtesy and support would enable affected people with rare diseases to get the right diagnosis, prevention, and therapy. We are looking forward to your response and would be deeply grateful for your positive feedback.

Thank you very much!

Family in danger – rare diseases affect children, adolescents, and adults

Account for donations: IBAN: CH50 0070 0110 0035 7775 0 − thank you very much!