



SPREADING OF THE AWARENESS ABOUT HUNTINGTON'S DISEASE

IN RESIDENTIAL CARE FACILITIES

BACKGROUND

Huntington's disease (HD) is a rare neurodegenerative disorder. Despite of a great health care in residential care facilities, the general awareness about HD specificity is very low in the Czech Republic. Therefore, we monitor current network of the care facilities which house/could house HD patients and we educate their personnel about HD and about the problems and needs of the patients.

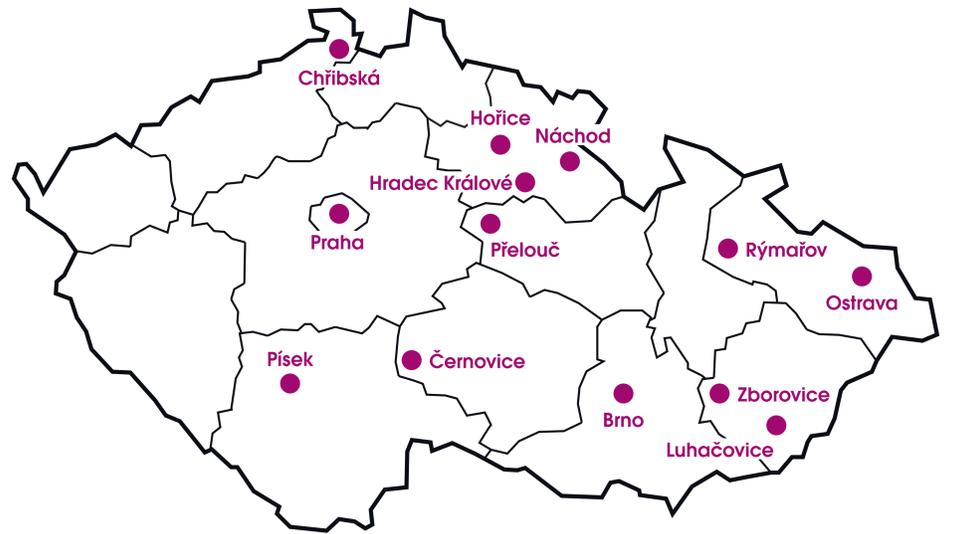


Fig. 1 Map of the cities where the lectures were realized in residential care facilities. Our aim is to cover all of the regions of the Czech Republic, what could offer the families a possibility to visit HD patients with limited consumption of time and travel costs.

AIM

To provide appropriate quality of life for HD patients housed in residential care facilities.

METHOD

Neurologist, professional caregiver and member of Czech Huntington Association have a set of 3 lectures for the personnel of residential care facilities. The lectures should enable to cope with the patient's admission and his subsequent care. We travel across the whole country in the effort to enable the frequent visits together with a cheap traveling for a short distances to the families.



Fig. 2 Rastislav Ostriz. Professional caregiver with a rich practice in caregiving about HD patients.



Fig. 3 Irena Liskova, MD. Neurologist with specialization on HD.

RESULTS

We educated more than 400 caregivers and social workers of 12 residential care facilities in the Czech Republic during last 2 years. Moreover, we monitor the care conditions and housing capacities in the care residential facilities.

Spreading of the awareness about HD in residential care facilities could help to increase the quality of life of HD patients.



Fig. 4 Lecture in one of the residential facilities.



Fig. 5 Our team – Rastislav Ostriz, Dr. Zdenka Vondrackova, Irena Liskova, MD, and Jiri Hruda.

CZECH HUNTINGTON ASSOCIATION AIMS V :

- quality of life and standards of care for HD patients in the Czech Republic
- active psychological support for people at risk and their protection against discrimination
- support for carers and children from HD families
- support for HD research together with patients' and their families' personal data protection
- education and raising of public awareness of HD

25th
anniversary
of establishing

SUPPORT

Ministry of Health of Czech Republic – supported by a grant from Switzerland through the Swiss Contribution to the enlargement European Union



Government of the Czech Republic, Elektrárny Opatovice

Úřad vlády České republiky



EOP ELEKTRÁRNY OPATOVICE

CONTACT

Czech Huntington Association, Velké náměstí 37/46,
500 03 Hradec Králové, Czech Republic.
monika.baxa@huntington.cz
www.huntington.cz, www.facebook.com/huntingtoncz