



Center of guiding

www.vzacni.cz

Web pages presenting rare diseases in patient stories + professional commentary.

Personnel

- 2,5 direct workers
- 0,5 health worker
- 0,5 psychologist

Basic facts:

- The expert center of the Society for Mucopolysaccharidosis
- Non-government, non-profit organization
- Situated in the Children's Clinic
- Contact: <http://centrumprovazeni.cz>, centrumprovazeni@seznam.cz
- Financial support: foundation, no state support

Target group:

- Families with children with rare diseases.
- Families with children with severe disabilities.
- Families of preterm infants and children with low birth weight.

Age:

- Children shortly after birth, younger school children, or even teenagers

Supply:

- Transmitting relevant and complex information to caregivers/parents.
- Sharing experience of other caring families, linking with other families.
- Psychological support, crisis intervention.
- Awareness raising in the field of relevant law, skills, knowledge, support of independence in order to manage the situation.
- Assistance in handling compensating aids.
- Accompanied visits to appointments with authorities and offices
- Accompanied visits to medical examination
- Assistance in getting social benefits.
- Assistance in making applications, appeals, administrative actions.
- Help with obtaining financial assistance
- Linking with local social services

Cooperation with Clinic

- Important role within communication the diagnosis (help with coping with difficult situation)
- Crisis intervention for parents
- Accompanied visits to medical examination
- not interference with medical processes
- Saves time for healthcare workers –enough time to answer questions
- Possibility of mutual consultation
- Feedback for doctors
- Education of health care workers

Czech Republic

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