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Rare Diseases in Young Children and Pediatrics Palliative Care in Kharkiv region of Ukraine

Ukraine, a country with a population of 45 million, does not have a national Pediatric Palliative Care (PPC) policy: no regulations, guidelines, education curriculum for medical students, nurses, physicians. The Kharkiv Regional Specialized Baby Home #1 (KRSBH) offers services about 300 children with special needs per year. In 2016 KRSBH start to support families by mobile palliative team at first in Ukraine. In 2016-2017 years there were 29 young children with rare diseases. Average age was 4,2 years. The distribution of disease was following:

Mucopolysaccharidosis type II (Hunter syndrome) and type III (Sanfilippo syndrome) - 2 (6.8%);

Spinal muscular atrophy (type 1 and type 2) – 5 (17.2%);

Cerebro-Oculo-Facio-Skeletal Syndrome (COFS) – 2 (6.8%);

Endocrine syndromes (Seckel syndrome,Prader-Willi syndrome, Turner syndrome, Noonan Syndrome, Pituitary dwarfism with malformations, Robinow syndrome) – 7 (24.1%);

Facomatosis (Klippel–Trénaunay syndrome and Tuberous sclerosis) – 2 (6.8%);

Other rare disease (Wolf-Hirschhorn syndrome, Freeman Sheldon syndrome, Leukodystrophy Krabbe, Dandy–Walker syndrome, Achondroplasia, Acrocallosal Syndrome, Townes-Brocks Syndrome, Congenital hypomyelination neuropathy, Apert syndrome, Rubinstein–Taybi syndrome, Crouzon syndrome) -11 (37.95).

During palliative care the palliative team must support parents and sibling. During communication we define their clinical and psycho-social-spiritual needs. One important issue of the parents was the question of the deep knowledge and understanding of the life-limiting disease in their child and the treatment policy in Ukraine and other countries. We found a lack of knowledge in this area.