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Background

Coordinating Centre for Children's Rare Diseases in Pediatric Unit of Vilnius University Santaros Klinikos has been established in 2012. There are more than 500 children with rare diseases that visit the centre annually. The hospital is also a member of 8 and an affiliated member of 7 European Reference Networks. Members of the Coordinating Centre have been working to improve support for children with rare diseases. One of such initiatives is Inpatient Day Centre, where children with rare diseases are treated since 2019.

Aims

We describe an inpatient day centre model which is used to provide multidisciplinary team (MDT) consultations in a single day and to organize weekly and biweekly enzyme replacement therapy (ERT) infusions for patients with rare and complex diseases.

Materials and methods

MDT consultations in the inpatient day centre are planned in advance. A timetable is prepared for one day's visits. Each patient and member of the MDT receive a personalized schedule, each patient also receives recommendations on how to prepare before the visit. By the end of the consultations, a MDT meeting is organized where all specialists gather to discuss recommendations for further care of each patient.

ERT infusions are also planned in advance. The patients and the nurses are informed about the patient schedule and planned tests. Upon arrival patients receive a check-up and an infusion is started. After the infusion, the patients are discharged and may resume their daily routine.

Results

Inpatient day centre requires additional preparations in advance, however, it results in a smoother experience during the patient's visit. Personalized schedules ensure timely consultations and MDT meeting leads to consistent recommendations. Planned ERT infusions also protect patients from unnecessary waiting time.

Conclusion

Inpatient day centre model has improved the care of children with rare diseases. It is a useful tool to help patients with rare diseases spend less time in a hospital and provide improved health-care quality. There are plans now to implement it into adult care as well.

ERN	Competence centre
ERKNet	• Rare kidney diseases and urogenital formation disorders competence centre
EuroBloodNet	• Onco-hematological diseases competence center • Pediatric onco-hematology and surgical oncology competence center • Hemophilia and clotting disorders competence center • Amyloidosis competence center
MetabERN	• Inherited metabolic disease competence center • Lipidology competence center
eUROGEN	• Rare urogenital diseases and complex disorders competence centre
ERN PaedCan	• Pediatric onco-hematology and surgical oncology competence centre
ERN TRANSPLANT-CHILD	• Pediatric onco-hematology and surgical oncology competence center • Congenital heart defects competence center
ERN-RND	• Huntington disease competence center
ITHACA	• Congenital developmental disorders and intellectual disability competence center
ERN-BOND (affiliated)	• Rare bone diseases competence centre
ERN-CRANIO (affiliated)	• Hearing impairment and hearing implantation competence centre
EpiCare (affiliated)	• Rare epilepsy competence centre
ERNICA (affiliated)	• Competence center for surgery of congenital anomalies in newborn
ERN LUNG (affiliated)	• Adults rare pulmonary disease competence centre • Cystic fibrosis competence centre • Pulmonary hypertension competence centre
ERN GUARD Heart (affiliated)	• Rare cardiovascular disease competence centre
ERN RITA (affiliated)	• Rare rheumatic and auto-inflammatory diseases competence centre

Table 1. Hospital's competence centres with ERN membership

Instructions for Spina bifida (SB) patients and their parents who arrive to the day centre

Visit date:

Visit time:

Consultation schedule:

Time	Specialist		Location
8:00 – 9:00	Initial check	Dr. 1	Ward
9:00 – 10:00	Pediatric nephrologist	Dr. 2	Room 503
10:00 – 11:00	Urologist	Dr. 3	Room 402
11:00 – 12:00	Rehabilitologist	Dr. 4	Room 411
12:00 – 13:00	Pediatric neurologist	Dr. 5	Ward
13:00 – 15:00	Patient discussion		

Fig. 1 First page of day center patient instructions