

EVALUACIJA PRVOG NACIONALNOG PROGRAMA ZA RETKE BOLESTI U SRBIJI (2020-2022): REZULTATI I OČEKIVANJA

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Retke bolesti (RB) su važan javnozdravstveni prioritet zdravstvenih politika na nacionalnom, evropskom i globalnom nivou. Specifičnost problema sa kojima se suočavaju oboleli od RB u Srbiji ogleda se u nizu nejednakosti ili nedostupnosti prava na zdravstvenu i socijalnu zaštitu. Inicijativom Ministarstva zdravlja RS i Nacionalne organizacije za retke bolesti u RS donet je prvi Nacionalni program za retke bolesti za period 2020-2022 (1). Opšti cilj Programa je: unapređenje zdravstvene zaštite i kvaliteta života lica obolelih od RB; a posebni ciljevi su: 1) poboljšanje prevencije i dijagnostike RB; 2) unapređeno lečenje, nega i socijalna zaštita obolelih od RB. Evaluacija Programa (2) pokazala je da: opšti cilj nije ostvaren, jer nije sprovedena anketa o stepenu zadovoljstva lica obolelih od RB. Evaluacija posebnog cilja 1 pokazala je da je potrebno bolja evidencija broja ljudi kod kojih postoji sumnja na RB. Evaluacija posebnog cilja 2 pokazala je delimično ostvarenje uz potrebu za izmenama određenih zakonskih propisa u oblasti lekova, biološkog materijala i pokazatelja o broju dana za koliko je terapija dostupna. Evaluacija prvog Nacionalnog programa za lečenje RB u Srbiji pokazala je da je neophodna bolja saradnja između institucija i udruženja pacijenata kako bi se podstakao napredak u ostvarivanju prava obolelih od RB.

Literatura

1. Program for rare diseases in the Republic of Serbia for the period 2020-2022. (Official Gazette of RS, No. 86 06.12.2019).
2. "Analysis and evaluation of the Program for rare diseases in the Republic of Serbia for the period 2020 - 2022". Available at:<https://norbs.rs/resurs-centar/#zajednozaretke#norbs#caring4rare#retkebolesti>

EVALUATION OF THE FIRST NATIONAL PROGRAM FOR RARE DISEASES IN SERBIA (2020-2022): RESULTS AND EXPECTATIONS

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Rare diseases (RD) are an important public health priority of Health Policies at the national, European, and global level. The specificity of the problems by RD patients in Serbia is reflected in a series of inequalities or inaccessibility of the right to health and social care. On the initiative of the Ministry of Health of the RS and the National Organization for Rare Diseases in the RS, the first National Program for Rare Diseases for the period 2020-2022 was adopted (1). The general goal of the Program is: the improvement of health care and quality of life of RB patients; and the specific goals are: 1) improvement of prevention and diagnosis of RD; 2) improved treatment, care, and social support of RD patients. The evaluation of Program (2) showed that: the general goal was not achieved, because no survey was conducted on the degree of satisfaction of RD patients. The evaluation of the special objective 1 showed that there is a need for better recording of the number of people with suspected RD. The evaluation of special objective 2 showed a partial realization with the need for changes in certain legal regulations in the field of drugs, biological material, and indicators on the number of days for which therapy is available. The evaluation of the first National Program for the treatment of RD in Serbia showed that better cooperation between institutions and patient associations is necessary in order to encourage progress in realizing the rights of RD patients.

References

1. Program for rare diseases in the Republic of Serbia for the period 2020-2022. (Official Gazette of RS, No. 86 06.12.2019).
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