

RARE DISEASES PATIENTS AS A VULNERABLE GROUP AND PROBLEMS IN THEIR TREATMENT

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The numerous improvements and innovations in the treatment of patients with rare diseases require continuous attention from the perspective of medical law regarding their healthcare. The vulnerability of this category of patients is highly pronounced and reflects various aspects of life and work, not just health. Numerous international and regional documents today provide protection to these patients, which was previously lacking and caused them great injustices. Legal aspects concern not only regulation but also the realization of basic rights, especially the right to access health care and the principle of non-discrimination. One example of legislative work is found in the law of Serbia, through the adoption of a special law concerning the diagnosis of rare diseases: the Act on Prevention and Diagnosis of Genetic Diseases, Genetically Caused Anomalies and Rare Diseases (2015). The provisions of the Health Care Act (Articles 11 and 72), the Health Insurance Act (Article 16), and the Patients' Rights Act (Articles 6 and 17) are also applied. Legal regulations provide for additional protection of certain groups for reasons of vulnerability. Criteria may include the age or life stage of the patients, as well as specific diseases. The vulnerability of some groups therefore exists on several grounds. In practice, the work of several Expert Centers for rare diseases is carried out at the tertiary level of health care and provides cross-border health care if necessary. The problems that arise in practice indicate that the condition for good protection of the sick lies precisely in compliance with regulations and the correct interpretation of basic legal institutes and concepts, which is the task of medical lawyers and all those working in healthcare.



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Abstract Title

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Abstract

The numerous improvements and innovations in the treatment of patients with rare diseases require continuous attention from the perspective of medical law regarding their healthcare. The vulnerability of this category of patients is highly pronounced and reflects various aspects of life and work, not just health. Numerous international and regional documents today provide protection to these patients, which was previously lacking and caused them great injustices. Legal aspects concern not only regulation but also the realization of basic rights, especially the right to access health care and the principle of non-discrimination. One example of legislative work is found in the law of Serbia, through the adoption of a special law concerning the diagnosis of rare diseases: the Act on Prevention and Diagnosis of Genetic Diseases, Genetically Caused Anomalies and Rare Diseases (2015). The provisions of the Health Care Act (Articles 11 and 72), the Health Insurance Act (Article 16), and the Patients' Rights Act (Articles 6 and 17) are also applied. Legal regulations provide for additional protection of certain groups for reasons of vulnerability. Criteria may include the age or life stage of the patients, as well as specific diseases. The vulnerability of some groups therefore exists on several grounds. In practice, the work of several Expert Centers for rare diseases is carried out at the tertiary level of health care and provides cross-border health care if necessary. The problems that arise in practice indicate that the condition for good protection of the sick lies precisely in compliance with regulations and the correct

interpretation of basic legal institutes and concepts, which is the task of medical lawyers and all those working in healthcare.

Key words: patients, rare diseases, vulnerability, regulations and practice, treatment problems

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