

University Hospital in Cracow





University Hospital in Cracow

- University Hospital in Cracow is a leading medical center and the biggest public hospital in Poland, not only providing therapy for patients but also training future medical staff.
- Hospital offers highly specialized medical care for out-patients and in-patients in the framework of different specialties represented by various clinical departments, laboratories and out-patient clinics.
- University Hospital based on the connection of three core tasks: patient care, education (training future medical staff) and research (including clinical trials). Academic teachers from Jagiellonian University Medical College (who simultaneously work in the Hospital as physicians) carry out research, conduct classes, and treat patients from the whole country.
- Each year, hundreds of future doctors and representatives from other medical professions receive their education in here.





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University Hospital in Cracow is the largest and one of the most technologically advanced hospital in Poland with:

- Clinical Departments - 34 (1315 beds in total)
- Institutes – 17
- Out-patient clinics - 71
- Intensive Care Department
- Hospital Emergency Department
- In 2023, more than 108 000 patients were hospitalized (excluding the Hospital Emergency Department) and over 540 000 outpatient visits were offered.





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- As a multi-profile facility, Hospital offers medical services in the fields of nephrology, cardiology, general and oncological surgery, gynecology and obstetrics, neonatology, otorhinolaryngology, pulmonology, immunology and allergies, internal medicine and geriatrics, urology, gastroenterology, infectious diseases, neurology, oncology, radiology, psychiatry, and rare diseases.
- The highly specialized Departments of Hematology, Neurosurgery and Neurotraumatology, Neurology, Metabolic Diseases and Endocrinology, Oncology and Intensive Care Unit play an exceptional role in the work of the Hospital.





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University Hospital in Cracow is a member of three **European Reference Networks for rare diseases** in the field of neurology, immunology and metabolic diseases.

MetabERN – European Reference Network for Hereditary Metabolic Disorders

ERN RITA – European Reference Network that aims at improving the care of patients with Rare Immunological Disorders.

ERN RND – European Reference Network for Rare Neurological Disorders





Rare Diseases Plan

- The current model of care for patients with rare diseases is not optimal, and the improvement of the situation of patients in Poland requires decisive action. Adopted in 2021 the Plan for Rare Diseases has not yet been fully implemented.
- The issue is therefore already in the development process.
- We expect the Rare Diseases Plan to be adopted by the Resolution of the Council of Ministers at the turn of April and May 2024, which means that the regulation will take effect in the second quarter of 2024.



Rare Diseases Plan

The Rare Diseases Plan defines six main areas for and a list of actions that need to be taken, as well as financing model for their implementation. The six areas covered by the Rare Diseases Plan are:

- criteria for the establishment and functioning of Rare Disease Expert Centres responsible for the supervision of the diagnosis, diagnosis and treatment of patients with rare diseases.
- definition of directions for improving the diagnosis of rare diseases, including access to innovative diagnostic methods using genomic technologies.
- proposals to improve access to medicinal products.
- establishment of a monitoring system for rare diseases through the creation of a Register of Rare Diseases.
- creation of individual medical documents containing clinical data, so called the *Rare Diseases Patient Passport*.
- creation of a Rare Diseases Information Platform, containing clinical, scientific and organizational information on rare diseases.

Benefits of being a member of the ERNs



- Access to international, highly-specialised multidisciplinary teams with a required concentration of knowledge and resources to treat a specific rare disease.
- Strengthening partnership and cooperation for research activities on rare diseases.
- Development and exchange of good practices and experiences.
- Development of good practices related to the treatment of patients with rare diseases (e.g. establishment of the multidisciplinary hospital team for rare diseases, keeping the rare disease patient registries that are valuable for research and evaluation of clinical care, identify and establish the *path of the patient with rare diseases*).

The challenges for the Joint Action on integration of ERNs



- Supporting the integration of the ERNs into the national healthcare systems will be the key to the successful development. ERNs should be further strengthened and integrated into general healthcare systems. Emphasis must be placed on the importance of collaboration between ERNs and national healthcare systems.
- The treatments and diagnostic are expensive and should be addressed at European level, to help cover costs not provided by national healthcare funding mechanisms (eg. development of structured, public health programmes and strategies to provide equal and reimbursed access to complex treatment).
- Enhancing cooperation between healthcare systems and European institutions in making the implementation of national plans for rare diseases more efficient.
- Priority must be given to make the patients with rare diseases more visible.



Conclusions

**A lot has already been achieved!
Still, there is much work to be done.**

By playing a part in the creating and planning process and sharing experience, we all make a personal contribution to the Joint Action on Integration of ERNs to national healthcare systems.

Marcin Jędrychowski, MBA

General Director of the University Hospital in Cracow