Ministerstwo
Zdrowia

POLAND25.EU

National Plan for Rare Diseases Poland 2024-2025

Urszula Demkow
Ministry of Health of Republic of Poland

RARE DISEASES - CHALLENGES

Equal and easy access to fast, innovative and reliable diagnostics, the best possible medical care and holistic support for every patient, regardless of the rarity of their disease.

A comprehensive, integrative approach to rare diseases, including education, research, prevention, diagnosis, care and treatment, social support and inclusion.

Ministerstwo
Zdrowia

POLAND25.EU

NATIONAL PLAN FOR RARE DISEASES in POLAND

1) Establishment of new Rare Disease Centers of Expertise (OECR) to cover the main clusters of rare and complex diseases
2) Improved access to diagnostic tests
3) Increased availability of medicines and foods for particular nutritional uses
4) Polish Rare Disease Registry (PRCR);
5) Rare Disease Patient Card;
6) Information Platform developing and disseminating knowledge about rare diseases.

Ministerstwo
Zdrowia

POLAND25.EU

NEW RARE DISEASE CENTERS OF EXPERTISE (OECR)

Currently 44 OECR w 23 hospitals **belong to** ERNs

Further OECRs outside the European Networks to provide patients with a specific rare disease or a group of rare diseases with access to diagnostics and highly specialized, coordinated medical care are being established.

The Rare Diseases Council is working on elaborating both substantive and formal criteria, to qualify the medical center as OECR.

Integrated care ensures that a patient receives joined-up care. It avoids the situation, where care is fragmented.

NEW financing solutions for OECR

The Plan assures financial sustainability of ERNs and OECRs

The new financial mechanisms for OECRs, aimed at covering the high costs of rare diseases patients management have been introduced.

The cost analysis was carried out in cooperation with the Agency for Health Technology Assessment and Tariff System (AOTMiT), the National Health Fund (NFZ) and experts, using the adopted rules of economic calculation.

Ministerstwo
Zdrowia

POLAND25.EU

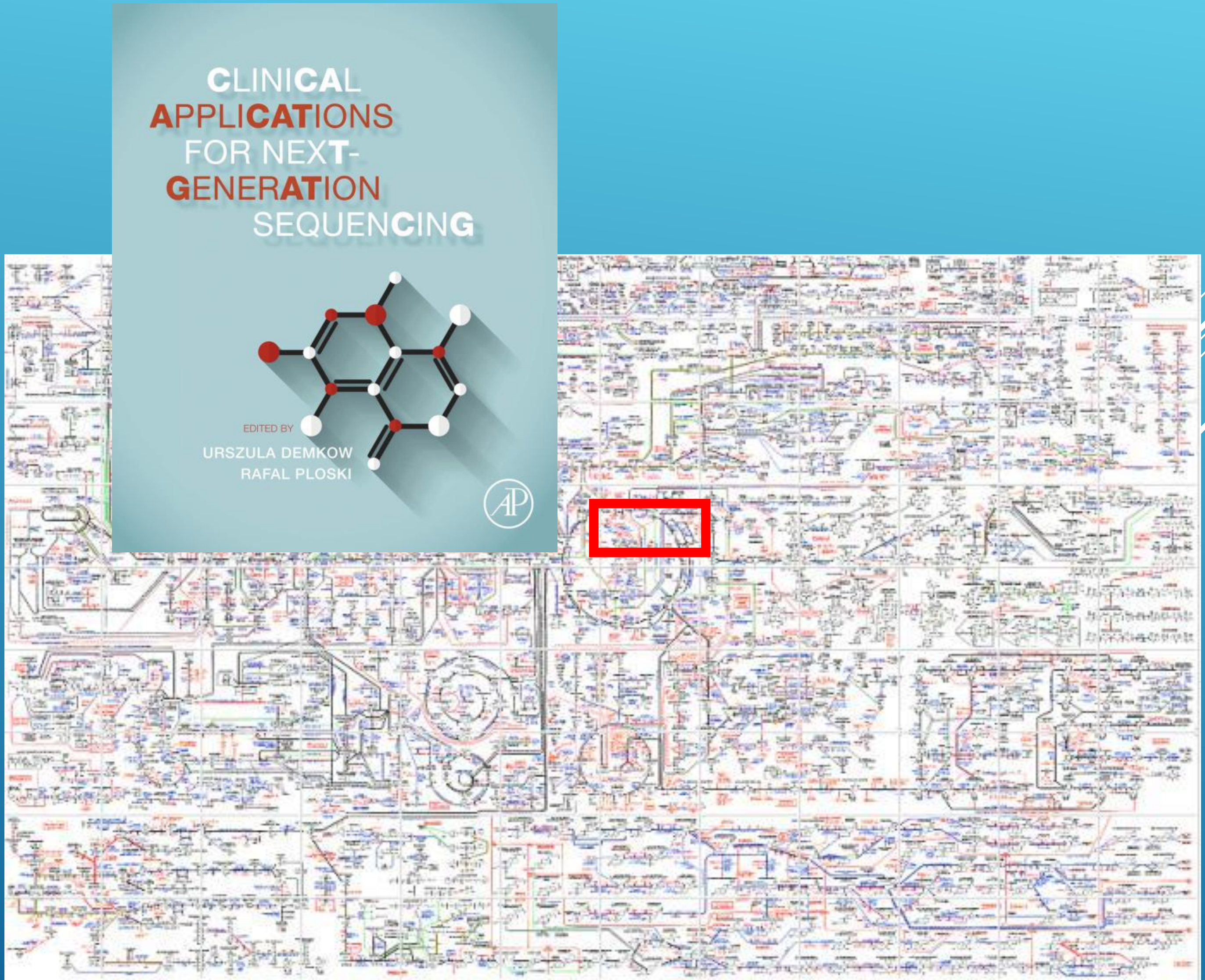
POLAND25.EU

IMPROVED DIAGNOSTICS – ESTABLISHEMENT AND FINANCING OF CERTIFIED LABORATORIES

gene panels, microarrays, exome sequencing

transcriptomics, metabolomics, proteomics,

functional studies to support the causality of a putative variant and understand the molecular mechanism of the rare disease.



CLINICAL APPLICATIONS FOR NEXT-GENERATION SEQUENCING

EDITED BY

URSZULA DEMKOW

RAFAL PLOSKI

Ministerstwo
Zdrowia

Improved access to drugs, medical devices and foodstuffs for rare diseases

Improved access covers innovative medicines (**registered** and at the stage of development or clinical trials **before marketing authorisation** and before obtaining reimbursement from public funds).

The introduction of legislative changes, which will enable **the implementation of newly registered drugs and technologies** with high level of innovation into the Polish reimbursement system.

Improving access to medicines and foodstuffs for particular nutritional uses imported as part of targeted imports.

Ministerstwo
Zdrowia

POLAND25.EU

Implementation of Polish Registry of Rare Diseases

1) appropriate and widespread coding of rare diseases (ORPHAcodes);
2) complete identification of patients with rare diseases;
3) properly defined sources of information about patients and refined logistics of obtaining data;
4) the activity of expert teams that can develop, interpret and use the data
5) appropriate authorization in the provisions of law;
6) stable financing.
7) searchable, findable rare disease registry data

The establishment of the Polish Rare Disease Registry (PRCR) will be in accordance with the FAIR principles and should be interoperable with EU registries

Rare Disease Patient Card

The Card will be kept in electronic form and integrated with the Individual Patient Account (IKP).

1) personal data

2) ORPHAcode, ICD-10 codes, possibly OMIM;

3) **recommendations and indications** for the patient, e.g. medicines, diet, vaccinations, etc.;

4) **contraindications** for the patient;

5) **Emergency Access**: contact phone number, diagnosis, recommendations and contraindications in a life-threatening state.

Ministerstwo
Zdrowia

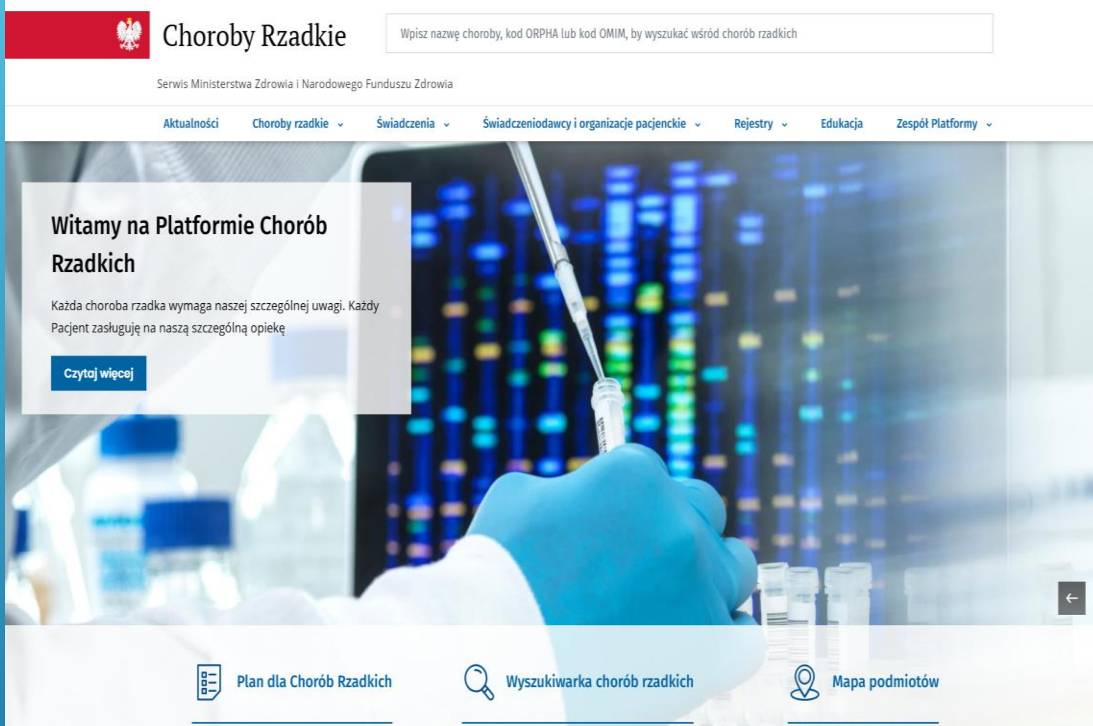
POLAND25.EU

Rare Diseases Information Platform www.chorobyrzadkie.gov.pl and outreach activity

The multistakeholders Platform is a reliable and comprehensive source of clinical, scientific and organizational knowledge on rare diseases.

Target groups using the Platform include:

- patients with rare diseases, their families and patient organisations,
- doctors and other healthcare workers, medical students,
- teachers (especially special education teachers), organisers and
- the general public.



Serwis Ministerstwa Zdrowia i Narodowego Funduszu Zdrowia

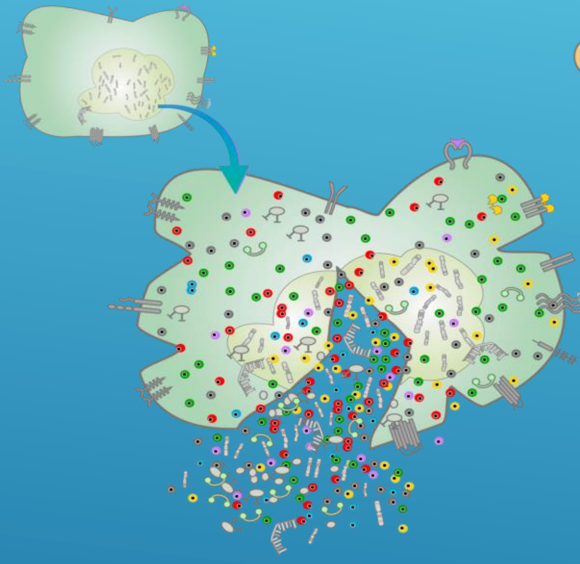
Witamy na Platformie Chorób Rzadkich

Każda choroba rzadka wymaga naszej szczególnej uwagi. Każdy Pacjent zasługuję na naszą szczególną opiekę

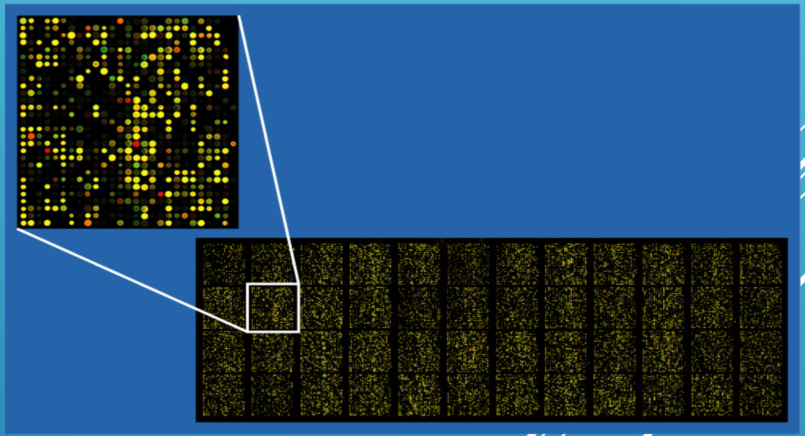
Ministerstwo
Zdrowia

POLAND25.EU

Artwork by Jeanne Kelly © 2001.



Artwork by Jeanne Kelly © 2002.



Ministerstwo
Zdrowia

Thank you

POLAND25.EU